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Life Interrupted: An Interpretative Phenomenological Analysis of Young People and their Family/Significant Other Living with Malignant Melanoma

Thesis submitted in partial fulfilment of the award of Doctor of
Philosophy (Ph.D.)

Wendy M McInally
May 2020

Declaration

I hereby declare that the work presented in this thesis has been conducted by myself.

This thesis has not been presented for any other academic award.

Wendy M McInally

Acknowledgments

In completing this work, I am indebted to all the young people, their families and loved ones who freely gave up their time and shared in great detail all their personal triumphs and setbacks experienced during their journey with malignant melanoma. This work would not have been possible without them.

To my supervisors, Doctors Richard Kyle, Carol Gray Brunton and Professor Zoe Chouliaria, I greatly appreciate the guidance and support you have provided during this daunting and on occasion overwhelming journey. Without your ongoing confidence and good humour this journey would have been even more arduous. I also would like to thank Doctor Jenny Murray who was the independent supervisor for this project.

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Abstract

Introduction

Melanoma is one of the most common human malignancies. Yet, it is often thought of as a disease of adulthood rather than one affecting children and young people. Although melanoma is rare in children, the incidence is rising in adolescents and young adults. Despite improvements in survival rates for young people, there is no evidence around the experiences of young people and their family/significant of living with this disease.

Method

A qualitative study underpinned by Interpretive Phenomenological Analysis was conducted using a novel multiperspective design to explore the experiences of young people and their family/significant other living with malignant melanoma in Scotland. Five young people were purposively sampled from three Scottish National Health Service Boards based on the treatment location. Each young person and a nominated family member/significant other were interviewed (n=10) either individually (n=4) or as a dyad (n=6). Semi-structured interviews were conducted, and, with the participant's consent, interview data were audio-recorded and transcribed verbatim and analysed. This identified key themes which were then clustered into four dominant super-ordinate themes and the findings distilled into an overarching metanarrative.

Findings

The metanarrative 'Life Interrupted' was the core conceptual thread woven throughout the findings. It represents the interconnections and interrelationships between the four identified super-ordinate themes that encapsulated the experience of young people living with malignant melanoma and that of their family/significant other: (1) 'Is it Serious', (2) 'Too Much too Young', (3) 'Not the Same', and (4) 'Time to Live'.

Conclusion

Being able to recognise and seek support in diagnosing malignant melanoma was challenging for young people and their families/significant other with limited physical, emotional or social support, often resulting in feelings of isolation. To overcome this lack of support and isolation, it is recommended that the care of young people and their families/significant other is seamless, and that clear links are established between services. Improvements to their journey can be made by focussing and addressing the experiences of young people and their family/significant other identified through this study.

Prologue

“The truth is of course that what one calls the interruptions are precisely one’s real life.”

C. S. Lewis, in a letter to his first and closest friend Arthur Greaves
on 20th December 1943 (Lewis, 2008 p.97).

I am Wendy McNally, a nurse, educator and researcher with over 25 years’ experience in the United Kingdom and internationally. I first encountered Malignant Melanoma (MM) professionally in my role as a paediatric oncology nurse. After moving into a Higher Education role at Edinburgh Napier University (ENU), my new academic purpose was to develop cancer education throughout the pre-and-post graduate curriculum. Throughout my earlier career, I have always worked with children, teenagers and young people from the ages of 0 to 25 years of age, either within the settings of a specialist children’s hospital or in the community outreach services. At the outset of this study, my initial assumption was that a MM diagnosis would be a catastrophic, life-ending event with no hope for this fatal disease. As my literature review progressed, it became clear that there had been no significant research into the experiences of an MM diagnosis within the TYA population, or their family, worldwide. MM is an under-explored type of cancer, particularly in terms of the lived experience. I was also interested in exploring this experience so that young people and their families/significant other living with MM could receive the same levels of recognition, support and treatment as other patients with cancer.

Current literature amongst young people is focused on particular Lymphomas, Central Nervous System (CNS) tumours and Leukaemia. In addition to this, discussing my research with other healthcare professionals further challenged my initial assumptions that MM in young people mostly resulted in poor outcomes. For example, as a paediatric specialist oncology nurse, I had attended a conference in Brisbane, Australia, in 2001. I can still recall one of the main presentations regarding MM, this being one of the gravest cancers for Children and Young People (CYP). At this time, MM was not something that I had come across within my practice or personally. In addition to this at the 2017 AYA Global Accord

international cancer conference, I met a young Australian man who been diagnosed as a child with MM but who had survived to reach the age of 26, was disease-free and was full of optimistic plans for his future. This one-to-one discussion fundamentally challenged my entrenched initial assumption that MM was a catastrophic, life-ending event.

My interest in MM unexpectedly arose in 1998 when my younger brother was first diagnosed at the age of 31 with Stage 2B MM. Subsequently, he was treated and supported through his MM experience, and a clinical trial for a new drug treatment, until his premature death of Stage 4 MM in May 2003 at the age of 36, leaving a 3-year-old child and young wife. In this particular instance, prolonged unprotected childhood and adolescent exposure to the sun was thought to be the primary cause of the disease. As an immediate family member, I experienced and endured the emotional roller coaster and feeling of helplessness that all families go through when a loved one is diagnosed with cancer. This experience helped me form a deep understanding of the challenges and difficulties faced by TYA and their families. Cancer does affect the immediate family, and this is also extended to other family members and friends. I can still recall the day I received the call from the GP in London. I was living with my brother and his wife at the time, and I received the telephone call to ask if he could go to the surgery immediately. The mole which had been excised the week previous had come back 'cancerous'. As they were on holiday, I had to wait another week before he returned. From there on in he received treatment and surgery to remove lymph nodes as the cancer had spread from the top of his left thigh to his groin area. This was in 1998, and by 2003 he was dead. Ironically it was the GP who had excised the mole who certified his death on the morning of the 11th May when he died.

My personal experience as a family member shaped this study and was the main justification for wanting to explore this area of care. However, I became aware of the increase in this disease within the UK and the disparity of the services available for young people and their families/significant other living with this disease. This study has captured the voices of both the young person and their family/significant other and how it impacts on the whole family/significant other.

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Glossary of Abbreviations

A

AYA.....Adolescents and Young Adults

B

BCC.....Basal Cell Carcinoma

C

CCLG.....Children's Cancer and Leukaemia Group

CINAHL.....Cumulative Index to Nursing & Allied Health

CLIC.....Cancer and Leukaemia in Childhood

CM.....Cutaneous Melanoma

CNS.....Central Nervous System

CNSs.....Clinical Nurse Specialists

CRUK.....Cancer Research United Kingdom

CTEC.....Clinical Trials Executive Committee

CYP.....Children and Young People

D

DoH.....Department of Health

E

ENT.....Ear, Nose and Throat

EONS.....European Oncology Nursing Society

ENU.....Edinburgh Napier University

F

FCC.....Family Centred Care

G

GLOBOCAN.....Global Cancer Observatory

GP.....General Practitioner

H

HEI.....Higher Education Institution

I

ICU.....Intensive Care Unit

IOG.....Improving Outcomes Guidance

IPA.....Interpretative Phenomenological Analysis

ISD.....Information Services Division

M

MM..... Malignant Melanoma

MSN.....Managed Service Network

N

NICE.....National Institute for Health and Care Excellence

NICR.....Northern Ireland Cancer Register

NMC.....Nursing and Midwifery Council

O

ONS.....Office of National Statistics

P

PIS.....Patient Information Sheet

PTC.....Principal Treatment Centre

R

RCN.....Royal College of Nursing

S

SACN.....The Scientific Advisory Committee on Nutrition

SCC.....Squamous Cell Carcinoma

SCC.....Shared Care Centre

SEC.....Standards and Ethics Committee

SIPAIG.....Scottish Interpretative Phenomenological Analysis Interest Group

T

TCT.....Teenage Cancer Trust

TCAT.....Transforming Care After Treatment

TYA.....Teenagers and Young Adults

U

UK.....United Kingdom

USA.....United States of America

UV.....Ultraviolet

W

WHO.....World Health Organisation

Y

YA.....Young Adults

YP.....Young People

Chapter 1

1.1 Introduction

Malignant Melanoma (MM) remains one of the most prevalent cancers in young people worldwide. The reported incidence continues to rise, despite global advances in cancer treatments, management and public awareness over the last 50 years (Hajdarevic, Rasmussen & Hornsten, 2014; McNally et al., 2014; World Health Organisation (WHO) 2019). This sustained upward global trend in the incidence of MM highlights the timeliness and importance of understanding the particular needs and experiences of this unique population.

This study explored the specific experiences of the young people and their family/significant other living with MM as they wrestled with its early indications and symptoms and how the diagnosis ultimately affected their lives. Over the next five sections, this Chapter introduces the unique characteristics of the young people, the age group definitions and terminology associated with describing this population. The background and incidence of MM in young people is explored globally, across the United Kingdom (UK) and within the Scottish healthcare system. The models of available care, including care transitions, are also considered. Specific evidence of the needs of young people with MM is scarce, but the demands for knowledge and understanding about the disease within this population are increasing, reflecting the changes in the global incidence of the disease. Consistent with the qualitative research tradition, my position as the researcher is explained within the Chapter. My prior assumptions, highlighted in the prologue, were fully considered within the overall context of the study. This approach sets the scene for the subsequent development of the research aim and questions. The final section of the Chapter outlines the full structure of the thesis.

1.2 Adolescents, Young Adults, Teenagers and Young People

Adolescents and Young Adults (AYA) are a unique group in society, perched on the cusp of no longer being a child but not yet fully an adult with all the independence and responsibilities this brings (Gibson, 2018; Smith, Davies,

Wright, Chapman & Whiteson, 2007; Smith, Mooney, Cable & Taylor, 2016). This transition is a momentous time and important life event in the developmental trajectory of AYAs. During this period, the young person is moving from dependence to independence (Arnett, 2000).

The WHO (2019) defines 'Adolescents' as individuals in the 10 to 19 years' age bracket and 'Youth' as the 15 to 24 years' age bracket. However, in other parts of the world, there is no apparent consensus on what constitutes a 'Young Adult'. For example, in the United States of America (USA), the term 'Young Adult' extends to the age of 39 years (Zebrack, Kent, Keegan, Kato & Smith, 2014). In England and Scotland AYA are considered to be within the age bracket of 15 to 24 years of age (National Institute for Health and Care Excellence (NICE), 2005; Scottish Government, 2016).

There is considerable confusion within the available literature on what terminology should be used to describe AYA. The idea of a young adult entering their adolescent years and demonstrating behaviours and attitudes that were not common in childhood or to the general adult population first appeared in the early 1900s. G. Stanley Hall (1904) first pioneered the discovery of the 'adolescent', presenting a definition of adolescence and establishing the 'normal and 'ideal' behaviours that characterised the developmental phase for this age group (Arnett, 2006). Hall's definition of adolescence initiated the idea of research into 'youth' and their behaviours, habits, and requirements. From his research, Hall suggested that the transition phase between childhood and adulthood was a time of 'becoming', when the fixed period of being a child came to a natural end through the emotional, physical and physiological growth into the adult state.

Adolescence has long been defined as a liminal zone (James 1986), a clearly marked space between childhood and adulthood (Arnett, 2006; Jaskulska & Mickiewicz, 2015; Janusz & Walkiewicz, 2018). This space is marked by a series of transitions that denote the movement from childhood to adulthood, from being dependent in childhood through to independence in adulthood (Marris, Morgan & Stark, 2011; Valentine, 2003). Valentine (2003) described this period for young people as one marked by a series of 'boundary crossings'. Importantly, these

boundaries are not merely imposed by adults but are in a constant state of flux and change, subject to repeated re-negotiation between the adolescent and the adult. The concept of liminality describes the time when people are on the threshold of entering a new phase in their life, having left the earlier one behind. This was first introduced by Charles-Arnold Kurr Van Gennep (1873-1957), a French-German-Dutch ethnographer. Gennep remains famous for his study of the rituals associated with 'the rites of passage' marking significant transitions in human lives, such as birth, puberty, adolescence, marriage, and death (Cheal 1988, Van Gennep, 1960). His work continues to be a significant theoretical and research construct, as is shown throughout this thesis. Victor Turner (1920-1983), a British interpretive anthropologist, builds upon Van Gennep's work and suggests adolescence is a 'rites of passage' and a transitional phase where the person is in a "state of progressive movement" to "becoming" a new self (Turner, 1964, p.46). In describing the transitional phase around adolescence, the term "teenager" is one of the more unusual inventions of the 20th century.

During the 1940s American publications began to use the word "teenager" to describe young people between the ages of 14 and 18 years (Savage, 2007). However, as a descriptor, the term 'teenager' did not gain any widespread recognition or acceptance until the mid-1950s (Weller, 2006) when the confluence of three trends in education, economics, and technology allowed today's idea of the teenager to form. Compulsory education to the age of 15 in the UK provided young people with a place to build a separate culture outside the watchful eye of family. Rapid economic growth in the post-war years provided an income, either earned or taken from their parents. The growing use of technology in society at this time, combined with a reduction in the statutory working week, led to a dramatic increase in the time available for leisure (Savage, 2007; Valentine, 2003; Weller, 2006).

As a life stage, adolescence is marked by a rapid phase of significant physical change, along with development in cognitive, psychological and social behaviours. For the young person, this can be a time of emotional turmoil, rapid physical development, and a time of growing self-awareness (Chisholm, Hough & Soanes, 2018). Understanding this evolving sense of self-awareness and individuality in

the young adult is essential if healthcare providers are to treat serious illness in a suitable and flexible way that recognises each young adult's specific needs.

For the purposes of this thesis, and reflecting the participant age group, the term 'Young People' (YP) is used as the consistent collective term rather than AYA (Adolescents and Young Adults), TYA (Teenagers and Young Adults), or YA (Young Adults). I refer to the age group as YP as the participants in this study were 16 years and over at the time of interview. According to Scottish Law, a child is defined as a person less than 16 years of age (Scottish Government, 2014). This definition is reflected in the current Scottish Government policy as set out in the Cancer Plan for Children and Young People aged 0 to 25 years (Scottish Government, 2016). Perhaps most importantly and tellingly of all, the YP participating in the study used the term 'young' or 'young person' rather than 'child,' 'adolescent' or 'teenager' to describe themselves and as such this seemed the most natural and appropriate term to use when representing their voice and experiences. The term 'family member' was used to refer to parents and commonly used by the YP in the study. 'Significant other' was used as a catch-all term to refer to the life-partner of one participant within the study.

1.3 Young People with Cancer Worldwide

The most recently reported figures from 2012 reveal that approximately 1,048,821 YP are diagnosed with some form of invasive cancer each year (Ries et al., 2017; GLOBOCAN, 2019). Within the UK, the incidence of cancer in YP is relatively rare but has shown a progressive rise from 14.4 cases per 100,000 of the population for those aged between 15 to 19 years and 22.6 cases per 100,000 of the population for those aged between 20 to 24 years. Cancer is the second most frequent reason for death in YP aged 15 to 24 years, accounting for 11% of all deaths (Birch et al., 2008; Kelly, Pearce & Mulhall, 2004).

More recent analysis from the UK, based on data extracted from the Information Services Division in Scotland (ISD), the Office for National Statistics in England, the Northern Ireland Cancer Registry and the Welsh Cancer Intelligence and Surveillance Unit, confirm that less than 1% of all new cancers diagnosed each

year are identified between the age of 15 to 24 years of age (Cancer Research United Kingdom (CRUK), 2019a).

Consequently, there are approximately 2,200 new cases of cancer reported in YP between the ages of 15 to 24 years of age in the UK each year (Children's Cancer and Leukaemia Group (CCLG) 2019, CRUK, 2019a). This compares to 1,600 new cases reported in children aged 0 to 14 years. Young people present with a spectrum of cancer types that are different from those affecting children and older adults. According to the ISD (2019), the most common diagnoses reported in YP across Scotland were carcinomas (21%), lymphomas (18%); and melanomas and skin cancers (16%).

Over the past 20 years, cancer care has improved for YP across the UK due to advances in medicine and advanced nursing practice alongside more focused policy (Department of Health (DoH), 2007; NICE 2005; Scottish Government, 2016). In Scotland, around 180 YP, aged 16 to 24 years, are diagnosed with some form of cancer each year (ISD, 2019), compared to approximately 130 children aged 0 to 15 years diagnosed with cancer (Scottish Government, 2016). With general cancer survival rates now exceeding 80%, there is a growing population of YP living with and beyond their cancer diagnosis and treatment, including approximately 14 YP living with an MM diagnosis each year.

1.3.1 Models of Care for Young People with Cancer

Young people with cancer experience a wide variety of different treatment and care processes and the needs of the family/significant other cannot be separated from that of the YP (Gibson & Soanes, 2008; Davies, Kelly & Hannigan, 2018; Morgan, 2018). The UK has been at the forefront of developing YPs services, where there have been several political drivers for change. The first driver for change was the Platt Report (1959) that drew attention to the specific needs of YP in hospital. The Platt Report commissioned by the UK Ministry of Health and formally titled 'The Welfare of Sick Children in Hospital', investigated the care of children in hospital and highlighted that children should be treated separately from adults. The committee, chaired by Sir Harry Platt, found that hospitals were

miserable places for children, where they were expected to conform to ward routines, not allowed to play; where to lie quietly was the accepted norm, and where, under no circumstances, were the parents allowed to visit outside the declared visiting hours. Despite the pioneering ideas of this early literature around caring for children in hospital and the role of the family, it would take many years before the revolutionary ideas contained within the report would be put into practice in the UK and in many other Western countries. By the early 1980s, changes began occurring rapidly with a new generation of doctors and nurses sympathetic to the main recommendations of the report (Taylor, Muller, Wattlely & Harris, 1999; Morgan, 2018).

The development of the Teenagers and Young Adults (TYA) care concept was first introduced into the UK during the early 1990s by the Middlesex Hospital in London, England with the specific purpose of meeting the distinct care needs of TYAs with cancer (Gibson et al., 2012; Morgan, as cited in Olsen & Smith, 2018). The DoH commissioned Calman-Hine (1995) report and outlined radical reform of the UK's cancer services to improve outcomes and reduce inequalities in NHS cancer care. This included how services for TYAs should be further expanded to include an environment staffed with suitably trained and qualified healthcare professionals (McInally & Willis, 2017; Smith et al., 2007). The Teenager Cancer Trust (TCT) charity has since taken the lead in driving these specialist services forward. Since that time, NICE (2005) and the Scottish Government (2016) has been instrumental in steering professionals in the care of TYAs with cancer. However, as these services have become more established, there has been a notable disparity in the definitions applied to the TYA group. For example, in England, TYA cancer care for YP aged 15 to 18 years with cancer must be referred to a Principal Treatment Centre (PTC). For those aged between 19 to 24 years, there is some choice available regarding their preferred treatment location, but the rest of the UK has yet to follow this lead (NICE, 2005).

Currently, there are 28 TCT units spread across the UK, and as seen in Figure 1.1, 23 are located in England, one in Wales and no current provision in Northern Ireland and four in Scotland. The UK is the only country currently to have such models of care for TYA, although work is currently being explored regarding TYA

units within some states of the USA (Teen Cancer America, Simon Davies, 2019). The number of YP diagnosed with cancer each year across England is approximately 2,600 (CRUK, 2019a). In Wales, 104 YP are diagnosed with cancer each year on average. The Cardiff children's hospital, opened in 2009, has a designated cancer service for children and young people as well as a TCT unit for YP aged 14 to 25 years. In Northern Ireland, the number of YP diagnosed with cancer each year is approximately 80 (CRUK, 2019a). The PTC in Belfast has two beds for teenagers, and young people and the acceptable range variation is from 13 to 20 years.

Figure 1.1 UK Teenage Cancer Trust Locations



Scotland has four TCT units, and the TYA age range is generally recognised as people between the ages of 16 to 24 (Scottish Government, 2016). It is fundamental to the patient's treatment and recovery experience that care is provided in a suitable, age-appropriate setting (NICE, 2005; Scottish Government, 2016). Many YP with cancer are not being treated within a setting appropriate for their age (NICE 2005), especially young people with MM. Many of these patients are also not considered for entry into clinical trials (Hollis & Hooker, 2009), which ultimately impacts on their overall cancer survival and recovery from the disease. It is important that as patients mature into adulthood, care pathways are clearly

defined (Maher & McConnell, 2011). These should consider the individual age, cancer type and the future risks of late effects from treatment as well as the personal needs of the young person and their family (DoH, 2007).

Comparing different international models of healthcare for YP is made more difficult by the differences in age group definitions. For example, in the USA, some individual State Healthcare Services extend the TYA age categorisation to 39 years of age (Zebrack et al., 2014). Despite varying definitions across the UK and globally, the fundamental strength of a TYA care model is that the patient can mature through their illness, developing coping strategies and a sense of self-worth and belief (Al Omari & Wynaden, 2014; Trevino et al., 2012). Supplying holistic care requires healthcare professionals to be highly trained, experienced and knowledgeable about the needs of this unique patient group and that of their family. This is a challenge within the UK as training and education for doctors, nurses and other healthcare professionals is subdivided into childhood and adult specialisms (Gibson et al., 2012). As a group, YP are often misunderstood by healthcare professionals due to a lack of both healthcare expertise and experience that recognises the age of the patient, the biology of the disease and the availability of clinical trials (Fern et al., 2013a). While striving for independence, autonomy and making decisions that affect their care, the young person is also, at times, dependent on their families (Soanes & Gibson, 2018; Trevino et al., 2012).

Caring for YP with cancer and their families requires a range of specific knowledge, skills, and experience to deliver these often-complex care regimes, both within the hospital and community environment (NICE, 2005). Policy reviews in cancer care across the UK have tried to ensure a single service throughout the treatment journey (Scottish Government, 2016; DoH, 2007). Initial cancer diagnoses are typically made at the appropriate PTC, situated within the local hospital. Delivery of treatment is dependent on the agreed treatment protocol and the needs of the patient and family, but generally takes place within either the Shared Care Centre (SCC) (a unit located within the hospital) or the home environment (Gibson & Soanes, 2008). Agreed treatment protocols available in the UK include the introduction of intensive multi-agent chemotherapy, combined with radiotherapy, surgery, bone marrow transplant and a recent addition is

immunotherapies (CCLG, 2019). These treatments meet and follow all necessary national and international standards (Gibson & Soanes, 2008; NICE, 2005).

Young people aged 16 to 24 years, with any type of cancer are a vulnerable group of patients with unique medical and psychosocial needs who are less likely to access optimal cancer services than any other group of patients (Gibson et al., 2012; NICE, 2005; Whelan, Dolbear, Mak, Møller & Davies, 2007). Providing national cancer services for YP is a particularly complex and challenging area of care requiring new clinical collaborations that straddle existing site-specific practice models, including paediatric, TCT units and adult services (Smith et al., 2016).

1.3.2 Transition of Care

Transition is an essential part of the cancer journey for each young patient, yet not all hospital services offer this (McInally & Cruickshank, 2013; Weston, Soanes, Chisholm, & Wiseman, 2018). The literature defines transition as “the purposeful, planned movement of AYA with chronic physical and medical conditions from child-centred to adult-orientated health care systems and should be a planned and regularly reviewed, to ensure a smooth transition to adult services” (Blum et al., 1993 p.2; Royal College of Physicians Edinburgh, 2008). This group of patients has been described as the ‘lost tribe,’ implicitly acknowledging there are no clear pathways of care in place as they transition from children’s to adult services within the cancer journey (Kelly & Gibson, 2008). Transition is therefore crucial for the YP with cancer, from the child to adult services and must be seen as a critical part of the cancer experience.

As YP transition to adult services, they are moving into a more independent and responsible phase of their lives and are encouraged to take responsibility for their own health care. It is crucial to empower these YP to make decisions about their health care, yet there is no transparent approach which may impact on their ability to achieve this (Davies, Kelly & Hannigan, 2015). McCann, Kerney & Wengström (2014) established that TYA require appropriate ‘readiness’ for transition to be effective. To allow for this preparation, healthcare professionals must strive to

ensure that the planning and preparation for this transition are communicated well before the actual transition occurs. A vital element of this success is for all health and social care professionals to work collaboratively together across children's and adult services. It should be recognised that an individual young person may find this emotionally and psychologically difficult and that further research regarding these specific challenges is required.

The majority of adult cancer care, in comparison to children's services, is delivered on a speciality focused basis, such as neurology or haematology. Young People report experiencing adult services as fraught with many difficulties and challenges, such as not being able to have a parent/carer stay overnight and restricted visiting during the day (Kelly & Gibson, 2008). Consequently, many patients and their families may have difficult transition experiences that negatively impacts on this crucial phase in their lives. For the transition of these patients with cancer to be seamless, healthcare professionals caring for this patient group and their families require a sound knowledge and understanding of the needs (Aldiss et al., 2015). This supports healthcare professionals to care appropriately and deliver a positive transition experience to the adult services.

1.3.3 The Family

The concept of family and what is commonly recognised as a family unit has evolved over the years. The term, 'nuclear family', coined in 1947, consisted of two biological parents with dependent children (Whyte, 1997). Today the family unit is more diverse, and society has changed since the 1940s (Whyte, 1997), the term 'household' now encapsulates the larger family unit. Cancer in YP is a family disease that affects not only the child or YP but the whole family (Grinyer, 2007). As the young person grows and develops into an independent individual, they are encouraged to take responsibility for decisions about their own healthcare (Davies et al., 2018). In part, this is dependent upon the age, stage, and severity of their disease. Although it is important to empower YP to make these decisions, there is little research on, or indeed clarity about, decision-making, their ability to take this responsibility or the impact these decisions have on the individual and their family (Davies et al., 2015; Wicks & Mitchell, 2010). This is important as the experience

of cancer can often occur at a time when YP are in the process of developing their early adult life plans (Taylor, Pearce, Gibson, Fern & Whelan, 2013). The diagnosis and subsequent treatment for cancer at this juncture may significantly impact their lives. In addition, a diagnosis of cancer at this time may add to the stressors associated with a 'normal' transition from child to young person and young person to adulthood as well as the impact on their relationships, quality of life and psychological wellbeing, amongst other components of their lives.

The needs of the family cannot be separated from the child or YP during this period. Feedback from children, YP and cancer charities has highlighted that they need support, space and a forum to discuss these issues (Cancer and Leukaemia in Childhood (CLIC) Sargent 2019; TCT, 2019). To ensure YP and their family/significant other receive timely information and support to empower them to make these decisions, further research into their specific needs and experiences to be undertaken (Davies et al., 2015).

The Family Centred Care (FCC) approach lies at the centre of children and young people's nursing within the UK (Darbyshire, 1994; Franck & Callery, 2004; Coleman, Smith & Bradshaw, 2003, Shields, 2015). The FCC approach directly supports the current view that involvement of the family is essential to the compassionate healthcare of children and young people (Fawcett, 2011). However, unclear conceptual definitions and inconsistent implementation remain despite FCC principles being encouraged since the publication of the Platt report in 1959. The concept of children and young people's nursing has deep roots within this model where healthcare professionals strive to work in partnership by negotiating the care where and when appropriate. This approach, however, differs for YP who may not be cared for within a children's hospital and therefore, experience a 'person-centred' approach to care (Kvale & Bondevik, 2008). This FCC approach becomes problematic in the TCT and adult services where the care is focused on the patient being empowered to take responsibility for their own health care and does not always include a role for the family. For example, within the children's service, the parents/family are encouraged to stay with their child and often make decisions together in recognition of the crucial role that the family plays in supporting and caring for the YP throughout their treatment journey.

Changes in the care delivery for individuals with cancer to one which promotes an FCC model where independence and self-awareness are encouraged and necessary may be problematic for some patients and their family (Hokkanen, Eriksson, Ahonen & Salanterä, 2004; Wicks & Mitchell, 2010). In dealing with the practicalities of supporting YP with cancer, families often express that it is “not clear who is in the driving seat” (Stuart Lawtie Conference, Mrs. Lawtie, 2016) when making treatment-related decisions. Services that are tailored to meet the individual needs of the young person and their family are necessary. The next section discusses YP and MM and is the focus of this study.

1.4 Young People with Malignant Melanoma

The incidence of MM is increasing globally and is affecting YP (CRUK, 2019b; Melanoma UK, 2019; McNally et al., 2014; Ferlay, et al., 2015). During the last decade, MM was rare in YP, with around 2% of all melanomas occurring in those aged less than 20 years (Bader, Li, Olmstead, Strickman & Green, 1985). Current evidence suggests that an MM diagnosed early can help ensure a positive prognosis and a healthy outcome (DoH, 2007; Scottish Government, 2016). Yet, if not diagnosed and treated with alacrity, the outcome can be fatal. Despite advances in MM treatments that have driven improved survival rates, the incidence of the disease continues to increase in several countries, due to a combination of factors such as UV exposure, familial traits such as hair and skin colour and other societal factors (Ali, Yousaf & Larkin, 2013). Young people are at risk, and these factors need to be taken seriously in the future (Kyle, Forbat & Hubbard, 2012).

There is considerable variation in the incidence of MM between countries (McNally et al., 2014; Ali et al., 2013). Rates of MM have seen a marked increase in YP who reside in developed countries (Downing et al., 2006, Purdue et al., 2006). This trend is attributed to variations in racial skin phenotype, as well as differences in sun exposure around the world. In the USA, for example, 98.2% of cases are reported amongst white-skinned individuals (Ali et al., 2013). According to a study by Mitis et al., (2015), MM is the second most usual form of cancer for people aged 15 to 29 years in the USA and the third most common cancer for young

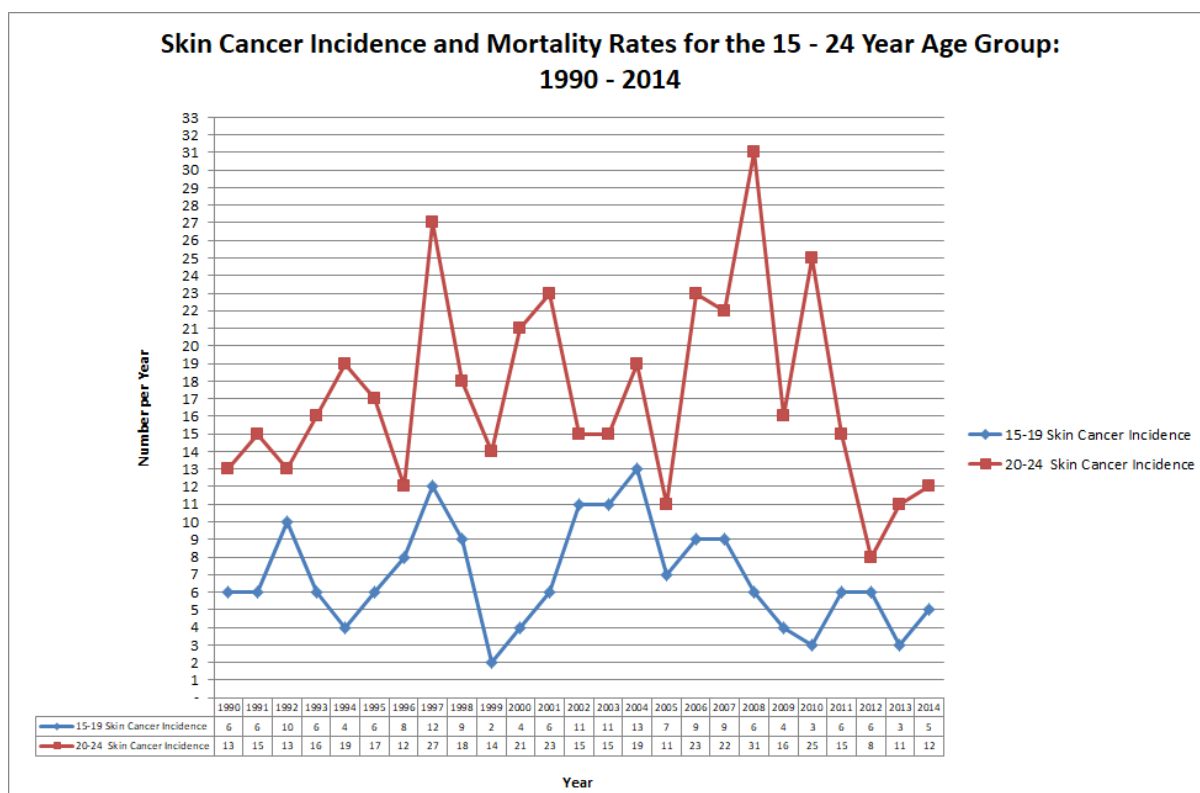
adults aged between 25 to 29 years of age in the UK. In the UK it is estimated that almost twice as many females (n=153) than males (n=73) are diagnosed with MM annually (CRUK, 2019b).

1.4.1 Young People with Malignant Melanoma in Scotland

Rates of MM are climbing, and Scotland has above average incidence when compared to the UK (Kyle, et al., 2014). Although more often diagnosed in older people, it is increasingly affecting the younger population with annual diagnosis rates growing (ISD, 2019). In 2019, new statistics revealed that MM is the third most prevalent cancer amongst young people in Scotland with 14 young people aged 15 to 24 years diagnosed with the disease each year (ISD, 2019). The situation in England is very similar, where MM is now the fourth most common cancer amongst young people (National Cancer Registration and Analysis Service, 2018).

In Scotland, of the 180 YP aged between 16 to 24 years diagnosed with some type of cancer each year, on average 14 YP, some 8%, are diagnosed with MM (Scottish Government, 2016; ISD, 2019). In 2017, there were no children under the age of 15 years, three YP between 15 to 19 years and 12 YP between 20 to 24 years were diagnosed with MM (ISD, 2019). The number of cases per year is higher within the 25 to 39-year-old age groups. In particular, young females are more at risk than young males. Survival rates in Scotland have risen by 21% over the past 20 years, from 64% in the period 1983 to 1997 to 85% in the years 2003 to 2007 (ISD, 2010; Kyle et al., 2014). Today MM is now the third most common cancer in the YP age group in Scotland (CRUK, 2019b; ISD, 2019). The current documented survival rate for YP diagnosed with MM is 95% (ISD, 2019), if the diagnosis is made sufficiently early in the life cycle of the disease to allow effective treatments and interventions to be introduced. Figure 1.2 charts the Melanoma/skin cancer incidence and mortality for YP living in Scotland between 1990 and 2014.

Figure 1.2: Melanoma Cancer Incidence and Mortality



The growing incidence of MM in Scotland is primarily due to several factors specific to Scotland's population, including environmental, societal and cultural conditions along with some genetic predisposition to the disease (Scottish Government, 2018). The combination of these factors presents a unique opportunity to understand better how YP and their families/significant other in a modern and sophisticated society cope with an MM diagnosis and how their lives are lived thereafter.

Young people are at a greater risk of MM than previous generations (Kyle et al., 2014) as today's media and 'celebrity' culture set ever-increasing body image expectations and demands. All media channels, particularly social media, bombard YP with images of tanned and thin people enjoying a lifestyle that is unattainable for the vast majority of the population. This pressure to be seen as beautiful and tanned poses a direct risk to the future health of YP if they succumb to these lifestyle pressures and expose themselves to harmful UV light. This pressure also extends to alcohol consumption, diet, exercise and other behaviours (Murray & Turner, 2004).

1.4.2 Epidemiology and Diagnosis of Melanoma

There are three main types of Melanoma skin cancer, basal cell carcinoma (BCC), squamous cell carcinoma (SCC) and cutaneous melanoma (CM). Although BCC and SCC are the most common, CM is highly malignant and requires an early diagnosis to prevent infiltration of the disease (McNally et al., 2014). There are a number of factors known to contribute to this disease, such as lack of awareness around the dangers of UV exposure, light skin colour, blonde or red hair, number of moles, family history, and of course actual excess exposure to ultraviolet (UV) radiation, particularly in childhood (Basta, James, Craft & McNally, 2011; Bader et al., 1985; McNally et al., 2014).

Although MM is more often diagnosed in older people, it increasingly affects YP. Malignant Melanoma has five main stages, ranging from Stage 0 to Stage IV. The categorisation, or staging, provides a standard way of describing the cancer, assisting healthcare professionals to discuss, treat and manage the disease in a consistent manner (Ali et al., 2013).

The stages and the general expected UK adult survival rates for each stage are noted below. However, it is worth noting that survival rate data for the various individual stages are not yet routinely available in the UK due to inconsistencies in the data collection (CRUK, 2019b).

- **Stage 0.** Refers to melanoma in situ, meaning the melanoma cells are found only in the outer layer of skin or epidermis. This stage of melanoma is unlikely to spread to other parts of the body. The expected general survival rate for Stage 0 is 100%.
- **Stage I.** The primary melanoma is still only in the skin and is very thin. Stage I is divided into two subgroups, IA or IB, depending on the thickness of the melanoma. The expected general survival rate for Stage I is almost 100%.
- **Stage II.** Stage II melanoma is thicker than Stage I, extending through the epidermis and further into the dermis, the dense inner layer of the skin. There

is a higher risk of spreading to other parts of the body. Stage II is divided into three subgroups—A, B, or C. The expected general survival rate for Stage II is between 80 – 90%.

- **Stage III.** This stage describes melanoma that has spread locally or through the lymphatic system to a regional lymph node. Stage III is divided into four subgroups—A, B, C, or D. The expected general survival rate for Stage III is greater than 50%.
- **Stage IV.** This final stage describes melanoma that has spread through the bloodstream to other parts of the body, such as distant locations on the skin or soft tissue, distant lymph nodes, or other organs like the lung, liver, brain, bone, or gastrointestinal tract. The expected general survival rate for Stage IV is between 10 and 25%.

Figure 1.3 illustrates the differences between each stage. The most important prognostic feature for YP with MM is the thickness of the primary tumour at diagnosis, and this determines the stage of the disease. The staging categorisation helps clarify the stage of disease for patients and healthcare professionals.

Figure 1.3: The Five Stages of Melanoma

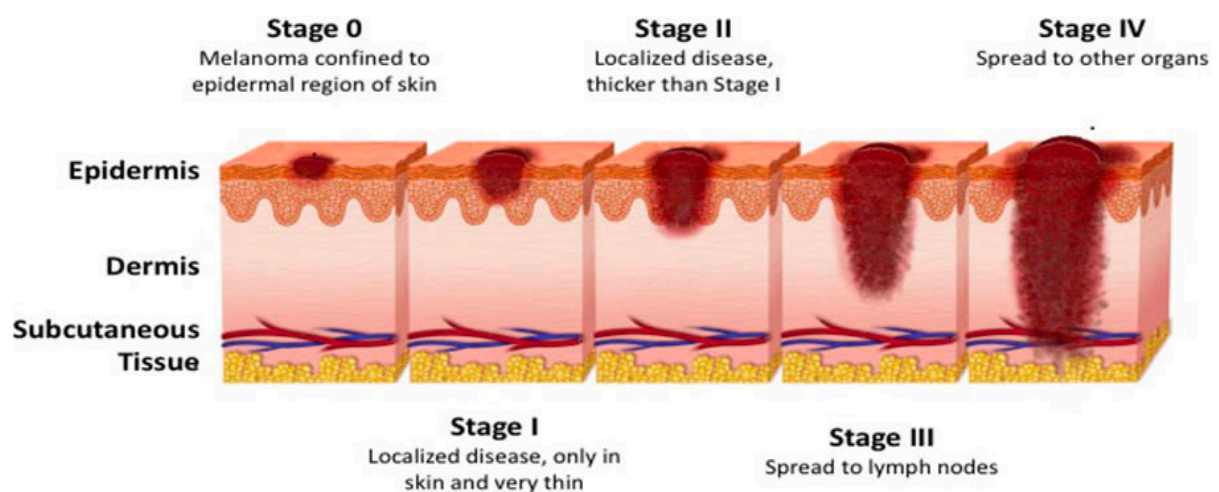


Image source: Jaworek-Korjakowska, & Kleczek (2018)

1.4.3 Management of Malignant Melanoma

Historically MM was seen as intractable and untreatable, whereas today, it is revealing its molecular weaknesses (Levy et al., 2018). Advances in clinical research mean that MM patients can now expect positive outcomes and a good quality of life (Hajdarevic et al., 2014; Weller, 2006). Curative treatment, however, is dependent on early diagnosis and the stage of the disease at the time of diagnosis, with the specific treatment dependent upon the stage of the disease (Office of National Statistics, 2016; Walter, Humphrys, Tso, Johnson & Cohn, 2010).

Young people with suspicious lesions are initially referred for further assessment by their GP or local dermatologist (CRUK, 2019b). There is little evidence or guidance on the treatment and management of YP with this specific disease. Children in Scotland under 16 years of age will typically be treated within the CYP services, whereas YP, aged over 16 years, will be seen within an adult service (Scottish Government, 2016). Young people do not always have access to specialist cancer services due to the treatment journey for melanoma being different from other forms of cancer. Most of the management for YP and their family/significant other is provided through outpatient appointments, depending on the stage of the disease. For all cases, treatment is usually a wide excision of the primary tumour with clear margins around the mole with no cancer cells evident. However, the definition of what represents a suitable clear margin and whether regional lymph nodes are affected and removed during surgical treatment is subject to extensive debate in the medical profession (CRUK, 2019b). Adjuvant therapy such as immunotherapy may be used as an additional treatment to supplement the primary excision for high-risk patients, but there is no standard practice in this area of care. Medical oncologists are trialling immunotherapy, which is expected to help substantial numbers of patients, but the best timing for this type of intervention has not been determined (O'Reilly et al., 2019). Systemic treatment is used in palliative and end of life care along with radiotherapy, especially for patients with metastatic disease (Levy et al., 2018). Some YP experience disease recurrence, undergo multiple surgeries and attend clinics for many years (Bird, Coleman & Danson, 2015).

In addition, the successful management of MM depends on the approach to care delivery. Recognition of early symptoms to ensure prompt diagnosis and treatment is crucial (Zebrack et al., 2014). Delivery depends on regular reviews of services and the identification of relevant treatment protocols and pathways in combination with a trained workforce to meet demand. This is a fundamental requirement so that YP and their family/significant other can be supported and prepared for their future. In Scotland, the cancer strategy focusses on enhancing multidisciplinary working across health and social care to ensure that YP receive care tailored to their needs (Scottish Government, 2016).

1.4.4 Government Policy in Caring for Young People with Malignant Melanoma

Government policy towards caring for YP with MM differs across the devolved nations of the UK. Healthcare policy in England and Wales dictates that the ideal treatment and care experience should be delivered from specialist centres and supported by other services that are age-appropriate (NICE, 20015; 2005; Smith et al., 2016; Taylor et al., 2013). However, there is limited evidence to suggest what is meant by 'age-appropriate care' and what this offers in comparison to other services for YP. 'Age appropriate care' and specialist services are not readily available for all YP with cancer across the world or indeed within the UK due to different devolved health care systems, resources and priorities (Birch et al., 2013; Pearce, 2009). There is also a need to address what happens in practice from the YPs' perspective and what information they receive about services for ongoing care and support (Taylor, Whelan, Gibson, Morgan & Fern, 2018). In England, 'BRIGHTLIGHT' has explored whether specialist services for TYA delivered any tangible difference to the YPs' treatment experience (Taylor et al., 2015). At the time of writing, the BRIGHTLIGHT research has yet to publish its final report. However, interim findings indicate that 'age-appropriate care' for YP is essential but depends upon a range of interdependent factors for its successful and sustained implementation and not all YP have access to these specialist services. The findings suggest that the benefits of 'age-appropriate care' can be

applied to many healthcare services, not just cancer (Lea et al., 2018). The publication of the final report is awaited with interest.

Currently, the Government in Northern Ireland has no policy in place but is in the process of preparing and reviewing specific guidelines for children and young people (CYP) with cancer (Cancer Focus Northern Ireland, 2019). In Scotland, Government policy is set out in the Cancer Plan for Children and Young People and aims to ensure that CYP between 0 to 25 years diagnosed with cancer have equal access to the best possible care and treatment as early as possible (Scottish Government 2016). The Managed Service Network (MSN) for CYP with Cancer has been charged with delivering this vision (Scottish Government, 2016). It is important that, as YP mature into adulthood, early diagnosis and defined care pathways are established. These pathways should consider the individual age, cancer type and the future risks of late effects from treatment as well as the personal needs of the young person and their family. The key driver to the policy is for CYP to be given the right diagnosis, the right treatment by the right team within the right place (Scottish Government, 2016). Within Scotland, it is recommended that each multi-disciplinary team has a Skin Cancer Clinical Nurse Specialist (CNS) whose role is to support patients and their families through the journey (Scottish Intercollegiate Guidelines Network, 146 2017). However, this policy is for adults only and does not apply to YP with MM.

A national review of services for CYP has provided an impetus for change in what has become a high priority area for the UK and Scottish Government and national charities such as the TCT, Macmillan and CLIC Sargent (Scottish Government 2016, NICE, 2005). Research has shown that after a cancer diagnosis YP are at significant risk of developing later life complications such as physical, emotional, and psychological trauma following their cancer treatment (Grinyer, 2007).

When considering skin cancer in Scotland, the key messages from the Government around the risks from UV exposure have changed. The most recent guidance on excessive sun exposure should be followed, but it is now recognised that some exposure to natural sunlight is essential to prevent a lack of Vitamin D in the general population (The Scientific Advisory Committee on Nutrition (SACN),

Scottish Government, 2019). Sunlight is necessary for the human body to produce vitamin D to prevent the onset of physical complications such as rickets in small children and osteoporosis in late adulthood. The Scottish Government (2019b) has recommended that everyone in Scotland have between 10–15 minutes of unprotected exposure to the sun each day. Sunscreen once applied to the skin, blocks vitamin D synthesis. Remaining in the sun for prolonged periods without the protection of sunscreen increases the risk of skin cancer, and Government advice on this remains unchanged (Kyle et al., 2014; Scottish Government, 2019b).

1.4.5 Research Rationale

Malignant Melanoma is an important disease within this age group, and awareness of the dangers of UV exposure is essential in addition to early diagnosis and care management within age-appropriate specialist services (Murray & Edgar, 2012). The YPs' experience of cancer is often at a time when they are in the process of developing their early adult life plans and are at a fundamental crossroads in their life. This study is concerned with the personal and relational impact an MM diagnosis can bring to YP and their families/significant other living in Scotland. As this disease continues to rise within YP in Scotland, treatment pathways and policy is changing. There is now a need to understand how YP and their families /significant other live with this disease. The fundamental purpose of the study was to gain an understanding and find meaning from the lived experience of each participant, as this is a poorly understood area of care. Understanding the impact on the individual sense of self and that of their family/significant other is critical if healthcare professionals are to deliver more appropriate care and support for young people with this disease in the future.

1.5 Position of the Researcher

The experience of living with MM is poorly understood with no international or national research focussing on the experiences of YP living with an MM diagnosis (McInally, 2018). This is also true for the experiences the families/significant other share with the young person endeavouring to cope with the disease. Reflexive

engagement with the available literature, detailed supervisory debates and interviews with the participants themselves allowed new understandings to emerge. The research revealed that some people positively embrace the challenges that an MM diagnosis can bring and regard overcoming the disease as a life-affirming event, encouraging them to live their lives to the fullest possible potential and not take life for granted. The personal value of this experience was the exposure, challenge, and changing of my own previously entrenched assumptions. This experience, and looking back on my reflexive notes, helped me become more aware of these assumptions and how deeply entrenched they were.

As the research progressed, it was important to guard against any elements of personal or professional bias creeping into the study. Although cognisant that my own experiences would help build empathy when meeting the young participants and their family/significant other, I proactively worked to minimise the risk of any undue influence affecting the outcome of this study.

Initially, I viewed the available healthcare structures through the prism of a specialist child health nurse, and not as the researcher. However, engaging with the literature, discussions with my supervisory team, reflexive diary reviews and attending a series of IPA workshops allowed me the opportunity to bring the personal voices and family experiences of the participant group to the front and centre of my research. My own experience of MM, as a family member, helped shape this study and was the primary motivation for wanting to explore this area of care. Although there is minimal research around YP with MM, there is equally limited research around the experiences of the families/significant other who must share the emotional trials of MM in someone they love. As this thesis developed and progressed, I was able to explore, challenge and revise my original assumption, as detailed in the Prologue, that every MM diagnosis in a young person led to an early death.

1.6 Structure of the Thesis

This thesis presents the results of an Interpretative Phenomenological Analysis (IPA) exploration into the lived experiences of YP diagnosed with MM and their

life-changing journey dealing with the unique challenges of this cancer during a time of transition into adulthood. The qualitative approach adopted, hermeneutic phenomenology and specifically the IPA allowed for the study participants to reflect upon their experience of living with MM (Smith, 2010). The participants core narratives help to articulate the meaning of their experience and the influential role played by the family/significant other in the MM journey. Literature was scarce about YP with MM, their lived experience and the impact this has on their immediate support mechanisms, such as their family/significant other. The impact on their immediate family/significant other is an essential dimension in their journey experience and as such, was a prominent consideration in this study.

Chapter 2 presents a review of the literature on YPs' experiences of MM and general cancers affecting this age group and summarises the current state of knowledge and understanding. The research strategies used to inform the narrative review are outlined within the Chapter. Based on the identified gaps in the current understanding of YP with MM, the literature review concludes with a rationale for this study.

Chapter 3 begins by stating the research aim and associated research questions that were developed from the literature reviews. It then discusses the research methodology and methods, along with the ethical considerations of the study. Throughout, I critically review and discuss the theoretical basis for the research design and approach and then explain the choices made in completing this study. Within this Chapter, I outline my efforts to achieve a deeper understanding of the participants' lived experiences through the phenomenological, hermeneutic and idiographic approaches of IPA.

Chapter 4 presents the findings from the study under the four super-ordinate and 12 sub-themes with extracts from relevant individual or dyad interviews to support the findings and the rigorous analysis, ensuring credibility and trustworthiness throughout. These findings lay the foundations for the metanarrative 'Life Interrupted' which is the core conceptual thread which is discussed further in Chapter 5.

Chapter 5 revisits the research aim and questions before discussing the core conceptual thread, the ‘Life Interrupted’ metanarrative. The main findings are illustrated through a conceptual representation and embedded within the four superordinate themes. These are then critically discussed and evaluated, exploring the meaning, importance and relevance of my research to theory and practice. In concluding this Chapter, I discuss my study’s original contributions to the broader body of knowledge, the strengths and limitations of the research, before highlighting and summarising my recommendations for future research, practice and policy. Finally, I present my overall conclusions from this research.

I end with an epilogue that bookends this thesis, highlighting my journey throughout, what I have learnt from undertaking this study and plans for future research.

Chapter 2 – Literature Review

2.1 Introduction

Chapter 1 outlined the context of the study, and positioned MM as a disease in YP which was rare during the 1970s but is increasing more rapidly than any other cancer in the UK. Scotland has an above average incidence when compared to the rest of the UK (Kyle et al., 2014; CRUK, 2019b, McNally et al., 2014) with no survivorship programme or long-term planning in place. Currently, the majority of YP are managed within the surgical skin/plastic department of their most conveniently located NHS Hospital with minimal contact with the UK's specialist cancer services. This Chapter aims to explore the existing literature and to understand what is currently known about the experiences of YP living with MM and those others most affected by this disease such as the immediate family (parents/carers, siblings and extended family members) and significant others (life partners, boy/girlfriend, close friends). These individual YP are still transitioning into adulthood and often require support and guidance from the family/significant other. From personal experience, as indicated in the prologue, cancer affects the whole family and significant others, including partners, loved ones and friends. Consequently, it was decided to include others within the young person's journey of living with MM.

Two separate literature reviews are presented in four distinct parts. Firstly, I set out the search strategy used to identify papers focused on the experiences of young adults with MM. As the initial search failed to identify any literature explicitly focused on the experiences of young adults/people with MM, the second literature review was widened to include young adult's/people's experiences of all cancers. Secondly, I discuss an existing meta-synthesis study which supports the second review. Thirdly, the search strategy used to identify papers for the second broader search and the literature, which focused on YPs experiences of cancer. Finally, I present an in-depth discussion of the papers for this narrative synthesis and review the overarching themes and subthemes that were identified around young adult's experiences of cancer and those of their family. This positions my study within the body of existing theoretical knowledge and research, and identify the

contribution my study makes to advancing the current state of understanding within research, practice and policy.

A sound understanding of the experience and specific care requirements of young adults with this disease, along with that of their family/significant other, is important if health and social care professionals are to base their future care plans on reliable and robust evidence. The focus of this study was to explore the lived MM experiences of YP and their family/significant other. Consequently, a qualitative research methodology was selected as the most appropriate way of exploring the lived experiences in a profound and meaningful way.

The role of the literature review in qualitative research has been widely debated. Some authors suggest that the literature review is best completed after data collection, with the grounded theory approach being one example of this (Polit & Beck, 2010). The rationale behind this view stipulates that an in-depth knowledge of the literature may limit the researcher's openness to new ideas. A possible consequence may be that the researcher becomes 'boxed-in' and unable to identify or accept challenges to their pre-conceived ideas and positions. Alternatively, a review of the literature prior to data collection offers the researcher the opportunity to fully explore what is known about the topic, identify gaps in that knowledge or understanding by reviewing the previous research and then provide an underpinning rationale for the study (Parahoo, 2014). Additionally, the literature review helps to contextualise and define the theoretical basis of the study.

Most qualitative methodologies reject formulating hypotheses before the research and instead promote an open inductive approach. This approach also helps identify any gaps in the researcher's knowledge and influences the methodology chosen to answer the specific research question(s). For these reasons, a literature review was undertaken before commencing the study. From the outset, it was clear there was a lack of research and evidence-based practice concerned with young adults with MM and those others affected by the disease.

2.2 Literature Review Approach

For the purposes of this Chapter narrative, integrative and systematic reviews were considered. As I was specifically concerned with the experiences of YP with cancer and of those affected by the disease, a narrative review was considered appropriate to identify only qualitative empirical papers. An integrative review considers both quantitative and qualitative research using different designs within the research process. In contrast, a systematic review brings together all quantitative research, and often utilises a common design, such as randomised controlled trials. Both integrative and systematic reviews were inappropriate (Grove, Burns & Gray, 2013) as these did not fit with my overall thesis and questions around MM. In addition, neither reviews matched with my stated inclusion and exclusion criteria. Ultimately, both approaches were disregarded as inappropriate for my literature review and not pertinent to the overall research aim and questions.

Qualitative research studies have become popular in healthcare, and have gained widespread acceptance within academic journals. Qualitative research focuses on the meaning and experience where quantitative research is scientific (Polit & Beck, 2010). These types of studies are designed to facilitate the collection of rich data in a non-threatening way (Bryman, 2008; Polit & Beck, 2010). Standard research methods adopted include individual interviews or focus groups where each participant can openly discuss their experiences or perceptions in a safe and non-judgemental environment.

Coughlan, Cronin & Ryan (2013) suggest a focused narrative review is a useful approach to providing a comprehensive overview of the literature while retaining many of the features of the systematic review approach. A systematic approach ensured my narrative review remained focused through specifying the exact parameters used in selecting the research papers for inclusion. The narrative review provided an overview of the current state of knowledge on the area of interest for the thesis and identifies areas for further study which subsequently informed the development of the overall aim and research questions which guided the study. The narrative review, informed by a meta-synthesis (Taylor et al., 2013)

was congruent with a rigorous, detailed and thorough examination of the available published literature. This approach considered the stated inclusion and exclusion criteria which are essential steps within this type of review. A narrative review seeks to 'summarise, explain and interpret evidence on a particular topic or question' using the qualitative evidence (Green, Johnson & Adams, 2006 p45). This was deemed as the most suitable type of review for this research.

2.2.1 Search Strategy

My review of the literature was carried out systematically between February 2015 and December 2017 using a range of databases, including MEDLINE, Cumulative Index to Nursing & Allied Health (CINAHL) and PsycINFO. As the research question was not solely about nursing, PsycINFO was included as an important resource when seeking YPs experiences as discussed in Chapter 1 section 1.4.5. In current practice, YP with cancer are cared for by several healthcare professionals, and it was therefore essential that all healthcare databases were included to capture all the various disciplines involved and not just nurses and the question focused on YPs experiences.

Review Question

Initially, the review question was: *"What are the experiences of living with malignant melanoma for young adults and their family?"*

A copy of the Medline search is shown in Table 2.1. Medline is the primary database providing full text for over 1,400 journals indexed within healthcare. Searches were conducted with the support of an expert Information Support Advisor through the Higher Educational Institution (HEI) Library, EBSCO database and catalogue.

Table 2.1: Medline Research Parameters

#	Query	Results
S8	S1 AND S5 Limiters - Date of Publication: 20000101-20171231; English Language; Human; Clinical Queries: Qualitative - Best Balance	40
S7	S1 AND S5 Limiters - Date of Publication: 20000101-20171231; English Language; Human	311
S6	S1 AND S5	628
S5	S2 OR S3 OR S4	786,475
S4	TI (child* or adolesc* or teenage* or young adult*)	784,110
S3	MM "Adolescent+"	5,518
S2	MM "Young Adult"	84
S1	(MM "Melanoma+") or "malignant melanoma*"	72,481

The search strategy used the following main terms to capture the largest number of relevant articles:

- disease ('skin neoplasm'; 'malignant melanoma');
- age ('child'; 'teenager'; 'young adult');
- relationships ('family');
- study design ('qualitative'); and
- focus ('experience').

MeSH terms were used as appropriate. Boolean operators 'AND' and 'OR' and wildcards were used to ensure maximum inclusion. In addition to database searches, experts who have written extensively within children and YP's cancer care were searched by hand to provide any additional papers that may have been missed. For example, Professor Faith Gibson and Dr Rachel Taylor, from the UK, Dr Roberta Woodgate from Canada and Professor Zack Zebrack from the USA. These are all well-known authors within this specialist field of practice. This activity identified no additional papers.

Study types included

All qualitative peer-reviewed primary research were included in the initial review. Papers relevant for inclusion needed to feature terms such as teenagers and/or young adults, or wildcard variations of other terms such as adolescent, YP, adolescent and YP (AYA) or teenager and young adult (TYA) in the title. This

approach was adopted early in the search process to narrow down the number of papers that were identified by the research.

Papers were deemed to be eligible for inclusion if published between February 2000 and December 2017. These specific dates are significant as qualitative research methodologies have become more widely conducted, recognised and published within healthcare over the past 15 years (Parahoo, 2014). Only research papers that were written in English were included.

Internationally, and particularly in the USA and Canada, people are recognised as a young person/adult up to the age of 39 years (Miedema, Easley & Hamilton, 2006; Zebrack et al., 2014). In order to be inclusive and not to omit any potential studies given the differences in this age group, all studies that included this upper age bracket were included. Young adults with cancer have also been given increasing recognition as having 'different needs' and as advances in treatment and models of care have evolved over the past 20 years (Taylor et al., 2013). Before these advances, the experiences of YP dealing with a cancer diagnosis is likely to have been very different from today's evidence-based approach (Taylor et al., 2013).

Study types excluded

This review did not include children aged under 12 years or young adults over 39 years. All studies that included young adults in the study but not in the research title were excluded. Studies that focused on YP with non-malignant cancers, other chronic illnesses, cognitive impairment and/or learning disability were also excluded. The study also excluded YP who had completed a course of treatment and had required no further interventions or disease recurrence in the past five years. There is a vast amount of literature around survivorship of cancer; however, this research was interested in the experiences of living with the disease and not the survivorship. All other types of research, editorials and policy were excluded, and the specific inclusion/exclusion criteria are shown in Table 2.2.

Table 2.2: Exclusion/Inclusion Criteria

	Exclusion Criteria	Inclusion Criteria
Age	< 12 to > 39 years	12 to 39 years
Population	Health Professionals, Nurse Doctor	Young Adult, People, Teenagers Family
Disease	Non-malignant, cognitive impairment, cancer	Malignant Melanoma
Diagnosis	>5 years of diagnosis	Within 5 years of being diagnosed
Language	Non-English	English
Publication date	Papers prior to 2000	February 2000 to December 2017
Papers	Quantitative Non-peer reviewed papers Expert opinion, review, meta-analysis, systematic review	Qualitative Peer-reviewed papers Primary research paper

Participants/population

There is a wide variation in categorisation and definitions used to describe this age group around the world, for example, teenagers, YP, young adults and adolescents, which was discussed in Chapter 1. I opted to use the term 'young adults' to cover the population aged between 12 and 39 years of age who had been diagnosed with MM. This definition was then used within the literature review to capture the necessary age group to ensure no studies were missed (Fern et al., 2013b, WHO 2019).

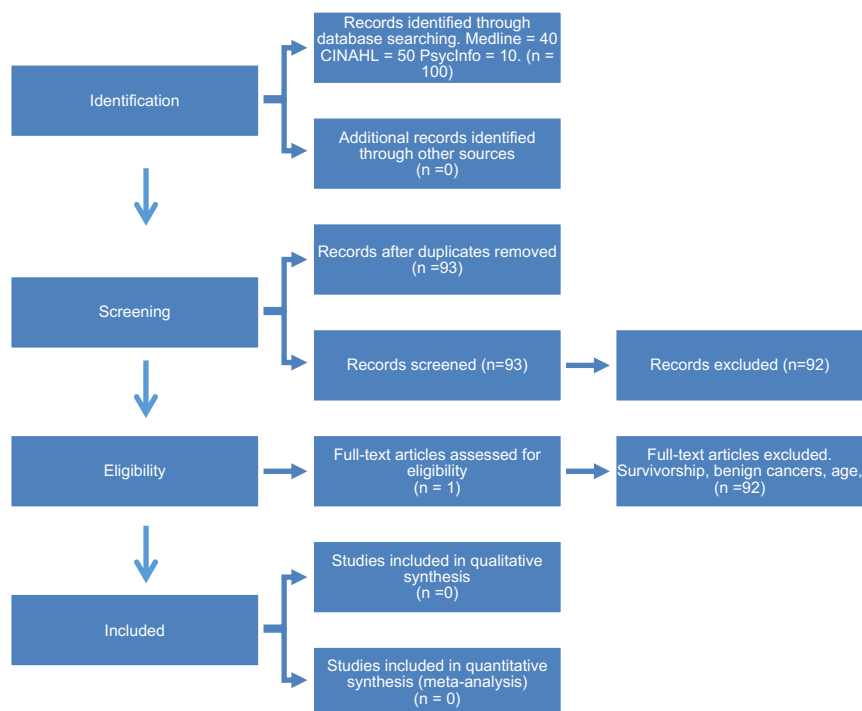
Family members were also considered within the literature review as they play a significant role in the cancer journey, especially if YP are still living at home. However, as the age range was extensive in this literature review, extending from 12 to 39 years, the inclusion of the family/significant other was not regarded as a compulsory factor for inclusion in my review.

Results

Initially, 100 articles were retrieved from the search (Medline n=50, CINAHL n=40 and PsycINFO n=10). From these 100 articles, 7 were duplicates and removed. A total of 93 abstracts were scrutinised and all the articles required for this review

identified. No papers relating to the initial question were found for this review, as shown in Figure 2.1 (PRISMA).

Figure 2.1: PRISMA 2009 Flow Diagram



Reference: Moher, Liberati, Tetzlaff, Altman (2009)

Figure 2.1 demonstrates that no international research papers reported the YP's experiences of MM or that of their family/significant other. Current research has tended to focus on the older patient with MM (Bird et al., 2015) and the experiences for YP living with other types of cancer such as Leukaemia and Lymphoma. As discussed in Chapter 1, Leukaemia and Lymphoma are more common than MM in the general population although the incidence of the disease is rising in this age group and there is a greater need for self-awareness and recognition of the early signs and symptoms of this disease. This increasing incidence of MM in this age group provides further justification for my thesis, participant group selection and the methodology chosen.

With this in mind, the literature search was widened to include all of YP's experiences of cancer. It was also the intention to include all cancers as the research papers may have included YP with MM in the data collection of these studies. On widening the search to include all cancers, a study by Taylor et al.

(2013) was identified as having conducted the most recent review of YP's experiences of cancer. I have included the Taylor et al. (2013) paper separately as this has supported the development of the second literature review.

2.3 The Earlier Meta-Synthesis Cancer Review

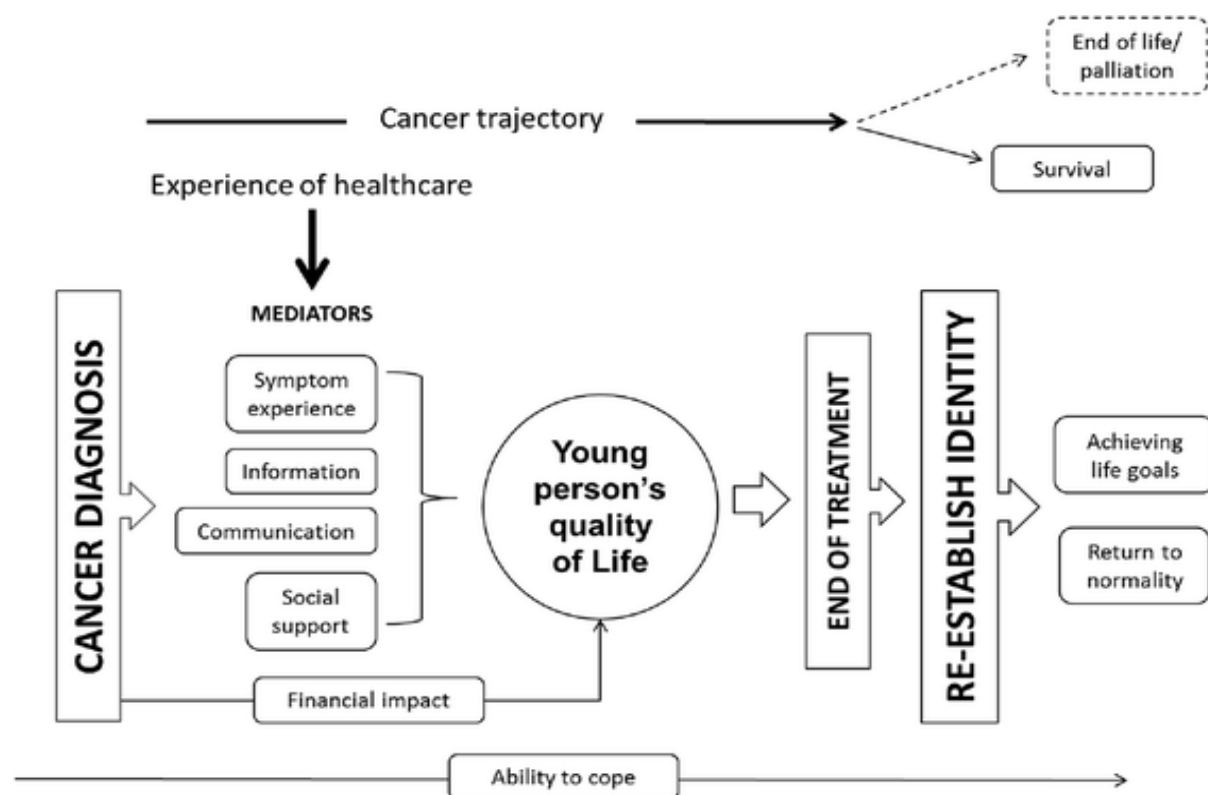
Taylor et al. (2013) study highlighted the findings of a meta-synthesis of the literature from 1988 to 2010 and proposed a conceptual model of teenager and young adult experiences of cancer. This model has directly supported the development and research of the BRIGHTLIGHT study, which sought to gauge how specialist cancer services in England impact on patient outcomes and experiences (Taylor et al., 2015). The Taylor et al. (2013) meta-synthesis included papers that were both quantitative and qualitative, although only the qualitative papers were extrapolated. The meta-synthesis was concerned with YP between 12 to 26 years of age. Taylor et al. (2013) study focused on individual cancers and did not consider the experiences of the family/significant other or the dynamic inter-relationships affected by the diagnosis.

Taylor et al. (2013) systematically reviewed 17 international papers, of which 59% were assessed as being high-quality research, and none rated as poor (Cesario et al., 2002). The primary cancers included within the papers were Leukaemia, Hodgkin's, Osteosarcoma and Ewing's. None of the papers included YP with MM or reviewed individual cancer-specific experiences separately. Nine themes were identified, and these formed the basis for the conceptual model proposed. The model was refined by the BRIGHTLIGHT user group who identified that there were gaps in the care delivery that require further exploration (Fern et al., 2013b). This is illustrated in Figure 2.2. Three of the studies included in this review are included in my second review (Hedström, Skolin & von Essen, 2004; Kelly et al., 2004; Wicks & Mitchell, 2010) as they met my inclusion/exclusion criteria.

Previous qualitative research has tended to study a range of different types of cancers in YP and their experiences, but there are strong arguments to suggest that there are unique aspects of different types of diseases/ cancers which none have focused on trying to understand. For example, the Taylor et al. (2013) review

has not explicitly sought to understand the experience of one type of cancer and what the impact has been for the young person and their family/significant other.

Figure 2.2: Conceptual Model - Taylor et al. (2013)



The model highlights areas of care that YP with cancer require to ensure their cancer experience is optimised. This study suggests that YPs psychological well-being is often dependent on receiving information from healthcare professionals in order that they can be empowered to take care of themselves and to continue to act as independent individuals regardless of their disease. However, Taylor et al. (2013) also stress the importance of recognising early symptoms in order that prompt diagnosis and treatment is available throughout the cancer journey (Hedström et al., 2004; Kelly et al., 2004, Wicks & Mitchell, 2010). Interestingly 'social support' as a mediator is included in the model but has not included the family/significant other as being important within the YP cancer journey, or the dynamic interrelationships.

Taylor et al. (2013) identified that as YP progress from diagnosis through to treatment and survival, the place of care, such as a specialist children's ward, Teenage Cancer Unit, or an adult ward, was an important consideration in their

overall cancer experience. Additionally, the delivery of care by suitably trained and experienced healthcare professionals plays a vital role in the cancer journey. Dedicated teenage and young adult cancer units were noted to have a series of additional benefits which outweighed the other treatment areas, in particular, the adult wards. Being with their peers, having access to healthcare professionals who were educated and trained to support YP all contributed to a better experience overall. There is recognition from the review that teenagers and young adults with cancer merit age-appropriate specialist care (Taylor et al., 2013) but the specific details of this remain unclear. However, outcomes associated with such specialist cancer care are not well defined (Fern et al., 2013b). Nevertheless, the Taylor et al. (2013) study has been the stepping-stone to exploring the YP's experience throughout the cancer journey. Through the development of their conceptual model, further research has taken place to examine the young person's experience and outcomes (Lea et al., 2018; Taylor et al., 2015).

2.4 Search Strategy

The paper by Taylor et al. (2013) supported the second review, and the literature search was widened to include all YP's experiences of all cancers by including 'neoplasm' and 'cancer' as there were no studies focused on YP's experiences with MM. With this in mind, this second review aimed to address the following question: *"What are the experiences of living with cancer for young adults and their family?"*

2.4.1 Types of Studies Included and Excluded

The same search strategy was carried out as per Section 2.2 However, this search was broadened to include 'neoplasm' and 'cancer'. A copy of the Medline search is seen in Table 2.3.

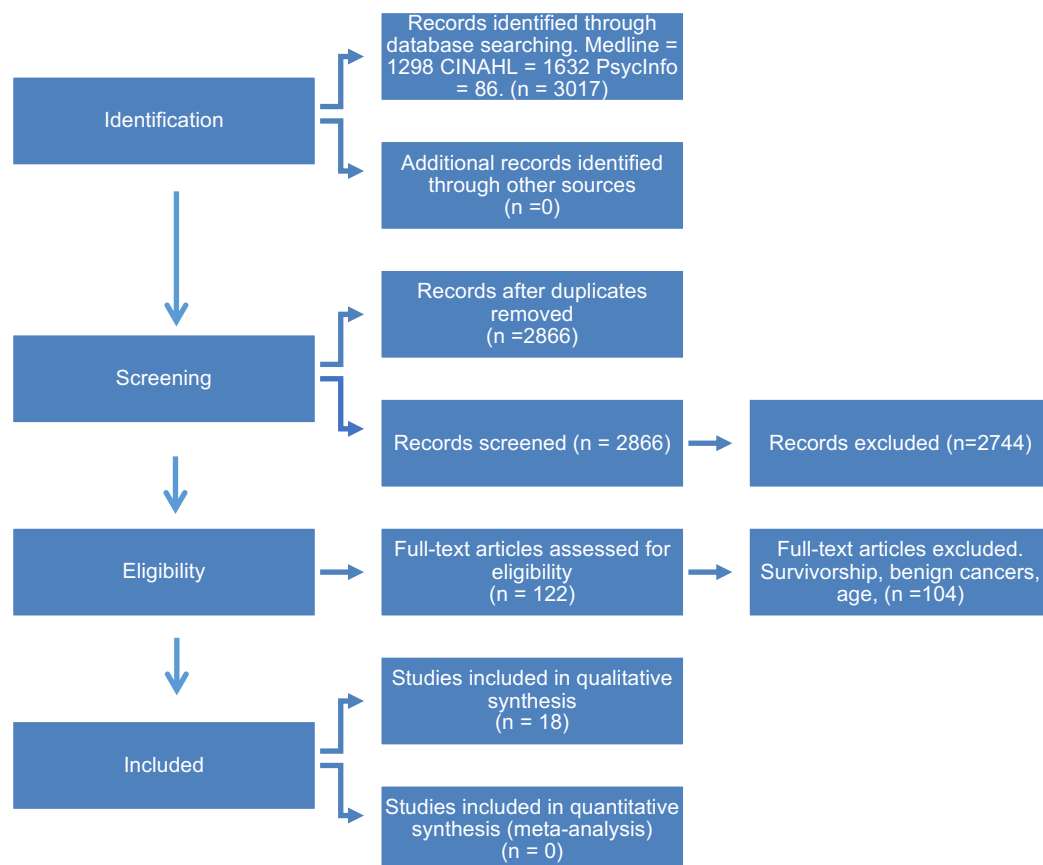
Table 2.3: Medline Search Strategy (EBSCO) September 2017

#	Query	Results
S19	S8 AND S16 Limiters - Date of Publication: 20000101-20171231; Clinical Queries: Qualitative - Best Balance	1,298
S18	S8 AND S16 Limiters - Date of Publication: 20000101-20171231	3,576
S17	S8 AND S16	5,169
S16	S1 AND S7	294,070
S15	S8 AND S12 Limiters - Date of Publication: 20000101-20171231; Clinical Queries: Qualitative - Best Balance	28
S14	S8 AND S12 Limiters - Date of Publication: 20000101-20171231	113
S13	S8 AND S12	148
S12	S2 AND S7	11,939
S11	S8 AND S9 Limiters - Date of Publication: 20000101-20171231	12
S10	S8 AND S9	19
S9	S3 AND S7	2,445
S8	(MH "Family+")	272,752
S7	S4 OR S5 OR S6	2,516,408
S6	TI (child* or adolesc* or teenage* or young adult*)	779,422
S5	(MH "Adolescent")	1,788,294
S4	(MH "Young Adult")	575,605
S3	"malignant melanoma"	25,137
S2	(MH "Skin Neoplasms+")	110,482
S1	(MH "Neoplasms+")	2,917,543

Results

Initially 3,016 articles were retrieved (Medline n=1298, CINAHL n=1632 and PsycINFO n=86). From the 3,016 papers, 151 were duplicates and therefore removed. 2,865 papers were screened with 121 abstracts being fully scrutinised for inclusion. Only 18 papers that met with the inclusion/exclusion criteria were included as per Figure 2.3, with the addition 'cancer' as the disease as opposed to MM. Endnote web was used to collect and file the finalised papers (Bryman, 2008).

Figure 2.3: PRISMA 2009 Flow Diagram



Reference: Moher et al. (2009)

2.4.2 Quality Assessment

Qualitative studies were assessed using the guidance framework provided by Popay et al. (2006). This was a useful vehicle for structuring a narrative review and increased transparency and rigour of the process. While there may be risks with over interpretation of study data, the framework supported the transparency and reproducibility of narrative review. An overview of the study characteristics is shown in Table 2.4.

Table 2.4: Characteristics of Reviewed Articles

Author / Date	Country	Aims	Philosophy / Theory	Age Group / Cancer	Study Design / Data Collection Methods
Al Omari, Wynaden, Al-Omari & Khatatbeh (2017)	Jordan	Explore - Coping Strategies of Jordanian Adolescents with Cancer: An IPA study	IPA	13 to 18 years Leukaemia n=4, Hodgkin's n=3 non-Hodgkin's n=3	In-depth individual interview of YP who were receiving chemotherapy
Al Omari & Wynaden (2014)	Jordan	Explore -The psychosocial experience of adolescents with haematological malignancies in Jordan; an IPA study	IPA	13 to 17 years Leukaemia n=6, Hodgkin's 5, non-Hodgkin's n= 3	Individual Semi-structured interviews, interviewed twice in 2 hospital settings six months after receiving a diagnosis
Farjou et al. (2013)	Canada	Understanding the healthcare experiences of teenage cancer patients and survivors from 3 paediatric hospitals	Open-ended survey	12 to 20 years Leukaemia n= 82, Lymphoma n=37, sarcoma n=30, brain n=25 other n=26	Open ended questionnaire 3 parts to it
Fern et al. (2013)	UK	The Art of Age-Appropriate Care: Reflecting on a conceptual model of cancer experience for teenagers and young adults	Qualitative Participatory Action	13 to 25 years Male n=5 Female n- 6	Semi-structured peer to peer interviews, workshop
Gibson et al. (2013)	UK	To describe how YP describe their prediagnosis cancer experience	Interpretive using narrative inquiry	16 to 24 years All solid tumours Ewing's n= 7 Osteosarcoma n=5, Hodgkin's n= 5, medulloblastoma n= 1 neuroblastoma 1, malignant peripheral nerve n=1, ovarian n=2, synovial sarcoma n=1, metastatic adenocarcinoma of bowel n=1	Semi-structured interviews 2-4 months from diagnosis of a solid tumour. Case notes were also accessed.
Hedström et al. (2004)	Sweden	Distressing and positive experiences and important aspects of care for adolescents treated for cancer. Adolescent and nurse perceptions	Cross-sectional descriptive	13 to 19 years Lymphoma n=8, Osteosarcoma n= 5, Ewing's n=2, Leukaemia n=3, other	Semi-structured interviews with an open-ended questionnaire YP and nurses.

				solid tumours n= 5	
Hokkanen et al. (2004)	Finland	Exploring what adolescents with cancer experience of life and how it could be made easier	Descriptive	13 to 18 years Leukaemia n=11, Hodgkin's n = 2, aplastic anaemia, non-Hodgkin's, brain and bone n=5 n=2 unknown what they had.	Focus groups attending cancer adjustment camp 3 focus group of 7
Kelly et al. (2004)	UK	Set out to provide insight into an adolescent cancer unit	Ethnography	13 to 20 years Cancers not known	Observation and in-depth semi-structured interviews with YP and parents
Kumar & Schapira (2013)	USA	Examine how young adult cancer patients make sense of their experiences with cancer.	Exploratory	18 to 30 years Ovarian n = 3, Hodgkin's n= 2, non-Hodgkin's n=1, Leukaemia n=3, melanoma n=1, breast n=1, endometrial n=1, ependymoma n=3	Semi-structured interviews
Kyngäs et al. (2001)	Finland	To describe the coping strategies and resources of YP with cancer	None	16 to 22 years Cancer lymphatic system n=5, Thyroid n= 2 Sarcoma n= 2 Leukaemia n=2 ovarian n=1brain n=1 granulocytoma n=1	Interviews
Miedema et al. (2006)	Canada	Young adults' experiences with cancer	None exploratory	20 to 43 years of age, various cancers and stages through to survivorship Hodgkin's n=5, Thyroid n= 2, breast cancer n=3, Synovial, melanoma, osteosarcoma, colorectal and fibrohistocytoma n=1	Individual Semi-Structured Interviews interviewed once
Olsson, Jarfelt, Pergert & Enskär (2015)	Sweden	Identify the requirements and acknowledge what is relevant to teenagers and YP	Exploratory	15 to 29 years Leukaemia n=12,	Focus groups 5 focus groups with 15-18 years (paed unit)

		treated for cancer in Sweden		Lymphoma n=11 sarcoma n=12, brain tumour n=2, Testicular n=5 gynaecological n=2	6 focus groups with 19-29 years)
Stegenga & Ward-Smith (2009)	USA	Explore the lived experience of being diagnosed with cancer from the perspective of the adolescent.	Phenomenology	12 to 17 years Cancer not known	Semi-structured interviews
Woodgate (2005)	Canada	Part of a more extensive study, this study, in particular, sought to understand the impact cancer and its symptoms had on the adolescents' sense of self.	Longitudinal	12 to 18 years Leukaemia or lymphoma n=12 Solid tumour n=3	Semi-structured interviews moderate participant observation and focus groups with one group 4 males and 1 group 5 females.
Woodgate (2006)	Canada	This paper explores the sources of social support that help YP get through their cancer experience.	Longitudinal	12 to 18 years Same participants as above	Open-ended interviews with follow-up questions and a focus group
Wu, Chin, Hasse & Chen (2009)	Twain	To describe the essence of the coping experiences of Taiwanese adolescents with cancer.	Phenomenology	12 to 18 years Leukaemia n=6 Brain n= 1, Neuroblastoma n=1, Lymphoma n=1 Osteosarcoma n=1	Interviews
Wicks & Mitchell (2010)	New Zealand	This study examined the adolescent cancer experience from the perspective YP.	None	16 to 22 years Leukaemia n=3 Lymphoma n=3 Brain tumour n=1 Bone tumour n=2 Germ cell tumour n=1	In-depth semi-structured interviews
Zebrack et al. (2014)	USA	To describe adolescent and young adult cancer medical care or experience with cancer	Survey open-ended questionnaire	15-39 years	Survey e-mailed

2.4.3 Rigour

The issue of quality in qualitative research has been debated over several years (Horsburgh, 2003; Rolfe, 2006). Qualitative research must address the issue of rigour if the study is to be judged trustworthy, credible and authentic (Rolfe, 2006;

Vivar, McQueen, Whyte & Armayor, 2007). Methodological rigour is, therefore, essential to produce high-quality research within this paradigm of research. There are a number of frameworks for assessing the quality of qualitative research. However, Rolfe (2006) suggests that there should be no rigid generic framework to establish rigour, as this has the potential to thwart the authenticity and creativity of the individual studies.

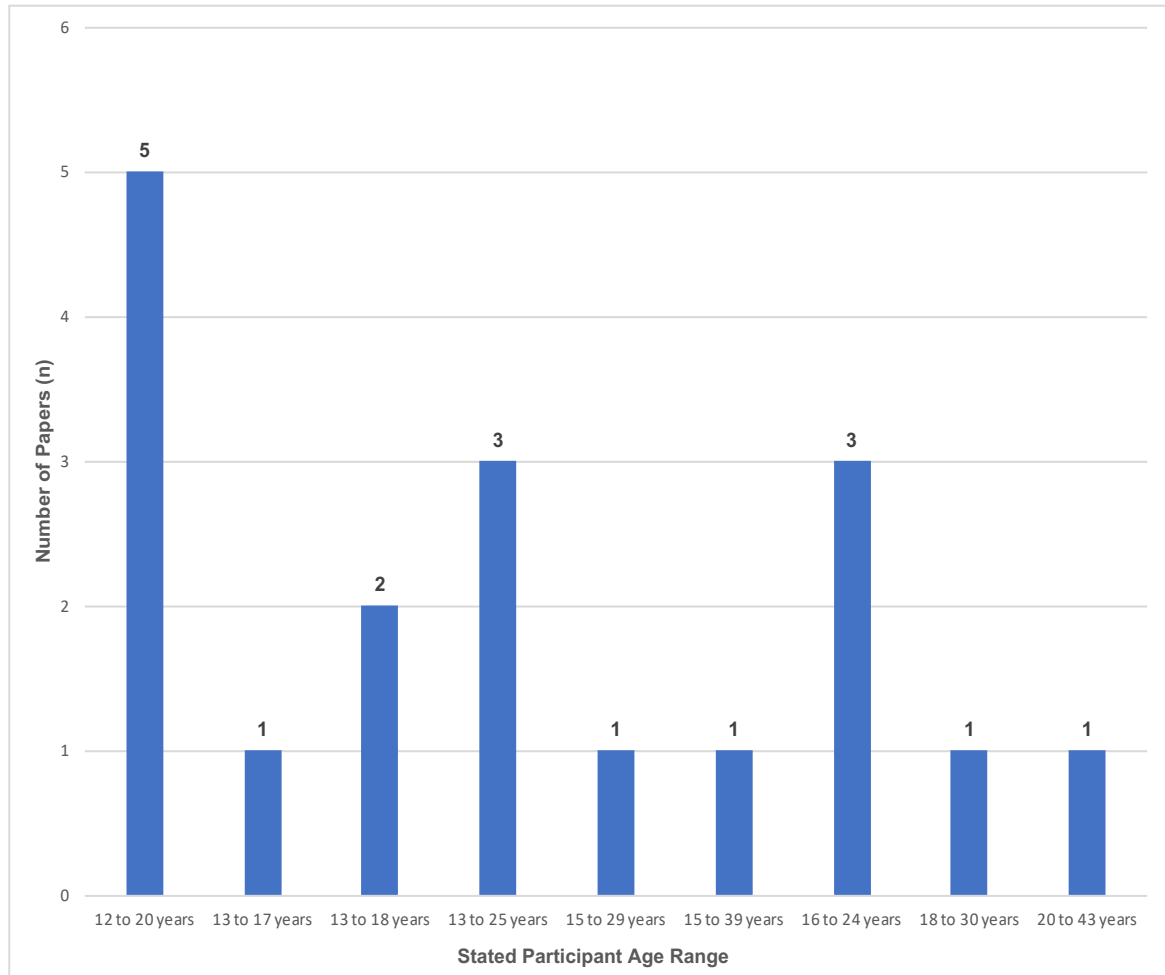
In considering this, I have chosen to use Guba & Lincoln (1994)'s four concepts of rigour to assess qualitative methodologies and ensure their trustworthiness. These are credibility, transferability, dependability and confirmability. This framework was used to assess the quality of each of the individual papers identified in the literature review. To ensure the credibility of the review, the researcher evaluated available frameworks and discussed these with supervisors. The credibility of each of the papers was dependent on independent analysis, ethical approval, and whether the findings were clear. In order to ensure transferability, constant checking was completed through a rigorous review of the papers. The transferability of the literature review was completed by ensuring that the findings were current and that the reported results were trustworthy and credible. Dependability and confirmability are continuous, and this was carried out through a constant update of the literature and being reflexive at all stages of the process (Morrow, 2005). Despite the general shortage of relevant literature on MM, 17 empirical papers were retrieved for this review.

2.5 Analysis of the Literature

The review includes four studies from Canada, (n=4), three from the USA (n=3), three from the UK (n=3), two from Sweden (n=2), two from Finland (n=2), two from Jordan (n=2), one from Taiwan (n=1) and one from New Zealand (n=1). A range of qualitative designs were applied, four (n=4) used phenomenology with two (n=2) specifically selecting IPA. One used a cross-sectional survey design, (n=1), two, longitudinal exploratory design (n=2), one ethnography (n=1), and two narratives and descriptive (n=2). Two papers identified no design but used qualitative exploratory methods and one action research (n=1). Only one paper included the family in their data collection, although three (n=3) mentioned the

family as being important within the data analysis. The age range of the participants varied, but the majority were in the age categories outlined in Figure 2.4.

Figure 2.4: Participant Age Range and Study Type



The Miedema et al. (2006) paper can be regarded as an outlier in terms of the age range. However, it was included as the vast majority of the 15 participants, some 14 people, were aged under 39, which met my stated inclusion criteria.

2.5.1 Synthesis of Findings

Using an inductive approach, the Popay et al. (2006) narrative framework, a systematic research review tool, allowed for the critique of each paper and for the overall synthesised themes to be identified. There are many such tools available for critiquing literature, with varying degrees of complexity. As my study utilised a

narrative review approach, the Popay et al. (2006) was the most useful in providing the necessary guidance and structure for my review. From each of the papers, the aim was to construct meaning from the narrative and illuminate an understanding. The researcher analysed and colour-coded the initial subthemes into a smaller number of the overarching themes. The themes reported in the identified studies are presented in Table 2.5 and are supported by relevant quotes reflecting the essence of each of the individual themes. The three main themes that emerged from the literature review are (1) being diagnosed with cancer, (2) uncertainty - holding on to life (3) gaps in care delivery.

Table 2.5: Emerging Cancer Themes

Study	Sample	Research Findings	Overarching Themes From Study	Sub-Themes From Review	Overarching Themes From Review
Al Omari et al. (2017)	10 YP 13 to 18 years of age, 5 males, 5 females	To cope with the impact of cancer, coping strategies emerged. There were some cultural issues faced within this study and the female participants.	Strengthening spiritual convictions Being optimistic and rebuilding hope Enhancing appearance Finding self again	Loss of oneself Hope and fear	Uncertainty – holding on to life
Al Omari & Wynaden (2014)	14 YP 13 to 17 years, 9 male 5 female	Participants reported limited emotional and psychological support from family, friends and healthcare team. Separated from family, friends once hospitalised. Treatment generated uncertainty of the future.	Being in the hospital, the changing self Fearing the unknown	Loss of oneself Hope and fear	Uncertainty – holding on to life
Farjou et al. (2013)	200 YP aged 12 to 20 years, 108 male 92 females	89% answered Q1 63% Q2, 69% Q3. This study was part of a more extensive teen-centred care study. Likes and dislikes were conceptualized into key themes. Support the shaping of future services for YP.	Staff at the treatment centre itself The cancer care they received, The treatments centre itself Social activities	Experience of healthcare delivery Age-appropriate specialist services	Gaps in the care delivery
Fern et al. (2013b)	11 YP aged 13 to 25. 5 male, 6 female	Built upon the conceptual model by Taylor et al. (2013) and identified areas of care that were deficient or unreported by YP experiencing cancer.	Diagnosis period Levels of information provided YP involved in research	Impact of diagnosis. Delay in diagnosis	Being diagnosed with cancer

		The diagnosis and information provided at this time was an important aspect of the cancer journey.		Experience of healthcare delivery Age-appropriate specialist services	Gaps in the care delivery
Gibson et al. (2013)	24 YP, 16 to 24 years, 14 male 10 female	Perspectives of the impact of the symptoms on their lives and in general, how others played a significant part. Findings report of the time lag from first symptoms to diagnosis. Age plays a vital part in this group patient as they are seeking independence.	The individual and nature of the symptoms Symptoms in relationship to other people Experiences of the generalist healthcare system Threshold points Specialist cancer care	Delay in diagnosis Experience of healthcare delivery Age-appropriate specialist services	Being diagnosed with cancer Gaps in the care delivery
Hedström, et al. (2004)	23 YP 13 to 19 years, 15 male 8 female	Findings indicate a range of positive and negative experiences related to the disease and treatment. Highlights the importance of information and the value of experienced staff that are competent in the care delivery.	Being told the diagnosis Receiving chemotherapy Being admitted to the ward Important aspects of care	Impact of diagnosis Experience of healthcare delivery Age-appropriate specialist services	Being diagnosed with cancer Gaps in the care delivery
Hokkanen et al. (2004)	20 YP 13 to 18 years, 13 female 7 male	Findings from the study report cancer experience can affect the adolescent's relationship with the world around self. Relationships with families were affected by the disease. They also found it hard to be independent.	Experiences of current life situation Future views Information received The need for additional information How life could be made easier	Family and friends Experience of healthcare delivery Age-appropriate specialist services Hope and fear	Being diagnosed with cancer Gaps in the care delivery Uncertainty – holding on to life
Kelly et al. (2004)	10 YP 13 to 20 years, 4 male 6 female 10 parents 9 mothers 1 father	Findings provide an insight into one specific cancer unit in London. The culture of the unit emerged as pivotal in supporting YP with cancer and through the expertise within the unit itself.	Cancer and the unit Changes over time	Impact of diagnosis Loss of self Hope and fear Experience of healthcare delivery Age-appropriate specialist services	Being diagnosed with cancer Uncertainty – holding on to life Gaps in the care delivery

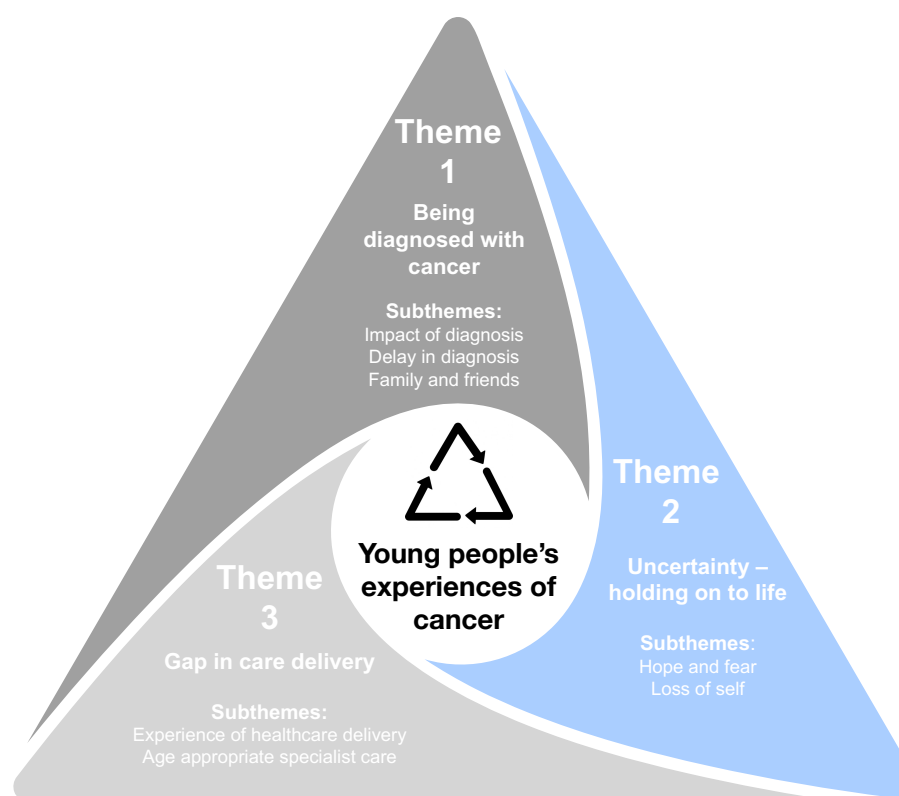
Kumar & Schapira (2013)	15 YP 18 to 30 years, 7 males 8 females	YP affected by the loss of physical control during and after treatment. Some found support from family and friends; others did not and felt isolated.	Intrapersonal, interpersonal, role identity	Family and friends Loss of self	Being diagnosed with cancer Uncertainty – holding on to life
Kyngäs et al. (2001)	14 YP 16 to 22 years of age, 6 male, 8 females	How YP coped with life and the coping strategies used.	Three significant strategies identified social support, belief in recovery and getting back to normal life as soon as possible	Impact of diagnosis Hope and fear Experience of healthcare delivery	Being diagnosed with cancer Uncertainty – holding on to life Gaps in the care delivery
Miedema et al. (2006)	15 YP/adult 20 to 43 years, 6 male 9 female	The most important issue that emerged was that being young appeared to delay in diagnosis: patients or physician's inaction.	Participant's age contributed to a delay in diagnosis either inaction from themselves, parents or physician	Delay in diagnosis Experience of healthcare delivery Age-appropriate specialist services	Being diagnosed with cancer Gaps in the care delivery
Olsson et al. (2015)	44 YP 15 to 29 years, 16 male and 28 females	The needs vary over time due to individual situations. HCPs need increased knowledge to care for this patient group. Special needs of this group are not being met in Sweden.	Personal & professional integration Knowledge and participation, Age-appropriate care Support	Experience of healthcare delivery Age-appropriate specialist services	Gaps in the care delivery
Stegenga & Ward-Smith (2009)	10 YP 12 to 17 years, 1 male 9 female	Findings suggest a loss of normalcy having been diagnosed with cancer is immense. Peer support fundamental and may support the loss of normalcy.	Loss of normalcy Gaining information Importance friends and their reactions Getting used to it, Giving back Family support	Family and friends Experience of healthcare delivery Age-appropriate specialist services Loss of self	Being diagnosed Gaps in the care delivery Uncertainty – holding on to life
Woodgate (2005)	15 YP 12 to 18 years, 8 male 7 female	Findings revealed that adolescents experience changes to their bodies because of symptoms and their increasing awareness of their body changing. HCPs to be in a position to recognise this and support where when necessary.	Ways of being in the world Still pretty much same person, well almost Respond as same person, but treat me as special	Loss of self	Uncertainty – holding on to life

Woodgate (2006)	15 YP 12 to 18 years, 8 male 7 female	This study found that families, special friends and HCPs were the three central supportive relationships YP experience. Although supportive at times, a source of stress.	Supportive relationships Being there Consequences of being there	Family and friends	Being diagnosed
Wu , Chin, Hasse & Chen (2009)	10 YP 12 to 18 years, 6 male 4 female	Findings suggest that there were many challenges of having cancer, especially ones they could not control. YP also felt that they required having hope as a useful coping mechanism to enable them to keep going.	Losing confidence Rebuilding hope	Hope and fear	Uncertainty – holding on to life
Wicks & Mitchell (2010)	6 male 4 female	Findings underline the need for effective communication, ongoing psychological support and service flexibility.	Treatment issues Hospital facilities Information provision Physical effects of treatment Emotional effects Impact on developmental processes	Impact of diagnosis Loss of self Experience of healthcare delivery Age-appropriate specialist services	Being diagnosed with cancer Uncertainty – holding on to life Gaps in the care delivery
Zebrack et al. (2014)	296 YP/adult 15 to 39 years, 192 male 104 female	Findings contribute to a better understanding of the cancer treatment experience.	Medical care domain Side effects and symptoms domain The psychological, spiritual domain Relationship domain Practical domain	Hope and fear Loss of self Age-appropriate specialist services	Uncertainty - holding on to life Gaps in the care delivery

These themes and subthemes are interrelated and summarised within Figure 2.5:

- **Theme 1** represents the beginning of the journey, being diagnosed with cancer.
- **Theme 2** denotes the uncertainty following the diagnosis and holding on to life.
- **Theme 3** is the gaps in the care delivery and highlights the parts of the cancer journey that were missing, for example, ‘specialist services’.

Figure 2.5: YP's Cancer Journey



While this figure has some similarities to the conceptual model developed by Taylor et al. (2013) as discussed in Section 2.3, there are fundamental aspects of the young person's psychosocial well-being that the review by Taylor et al. (2013) did not capture. It is also interesting to find that none of the literature from Taylor et al. (2013) or the researcher's second review explicitly discussed the experiences of a young person with MM. Young people experience the three themes identified at different times and stages of their disease and were unlikely to emerge in any chronological order.

2.6 Being Diagnosed with Cancer

While cancer is relatively uncommon in the general population of YP compared to adults, YP reported that receiving a cancer diagnosis was the most challenging part of the cancer journey. This experience was compounded by the need to wait for an appointment or starting their treatment. Being diagnosed with cancer was mentioned in ten of the studies (Fern et al., 2013b, Gibson et al., 2013, Hedström et al., 2004, Hokkanen et al., 2004, Kelly et al., 2004, Kumar & Schapira, 2013,

Miedema et al., 2006; Stegenga & Ward-Smith, 2009; Woodgate, 2006; Wicks & Mitchell, 2010) and each of these are critically discussed under the three subthemes. The three subthemes included: impact of diagnosis, delay in diagnosis and family and friends. These studies identified that the impact of a diagnosis combined with a delay in diagnosis was an integral part of the overall cancer experience and journey. Family and friends were also an important part of this journey, from diagnosis to living with cancer and beyond. Young people reported that it was their immediate family and friends that were important in facing the future as they had been involved from the beginning.

2.6.1 Impact of Diagnosis

Being diagnosed with cancer can impact profoundly on the young person's life (Fern et al., 2013; Hedström et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Wicks & Mitchell, 2010). Fern et al. (2013b) aimed to refine the conceptual model, which was developed by Taylor et al. (2013) from a meta-synthesis. This study built upon the model, identifying areas of care that were deficient or underreported. Poor experiences of the journey to diagnosis were reported using action research with eleven YP (n=11) aged between 13 to 25 years in England. Although the paper states they involved YP who were cancer survivors, ten (n=10) YP were treated for cancer within the 5 years. This study was unique in that they trained the YP in research methods so they could be an active part of the study. These YP participated in peer to peer interviews, followed by a workshop. This research built upon the conceptual model as discussed as a bridge to this narrative review (Taylor et al., 2013). Although a small sample of YP from England, this study reported on the diagnosis period as being an important aspect of the cancer journey and the level of information received. Both the Fern et al. (2013b) and the Taylor et al. (2013) studies informed the survey development for a longitudinal cohort study examining patient experience and outcomes, which was part of the BRIGHTLIGHT study.

Hedström et al. (2004) used a cross-sectional descriptive survey and undertook open-ended interviews with 23 YP with cancer and 21 nurses. This study was carried out in Sweden within paediatric units with YP, aged 13 to 19 years. This

study found a range of positive and negative experiences that individuals faced, such as being diagnosed, receiving chemotherapy, ward admission and other important aspects of the care delivery. This study, however, did not include YP being cared for within non-paediatric settings. This may be because there are no young adult cancer units in Europe.

Similar findings to this study were reported by Kyngäs et al. (2001). This research involved 14 YP, aged 16 to 22 in Finland and aimed to define coping strategies and resources that YP with cancer require to support them at the time of diagnosis. Through their descriptive approach, they found that it was often how the diagnosis was delivered, often over the telephone and by a healthcare professional who did not know them. Often, the young adult would then have to wait days before they were seen and were left to worry about cancer and its possible impact on their life. As a result, YP felt unable to ask questions about their diagnosis or seek clarification around the nature of their disease. This was an important, but missing, part of the cancer journey for all YP. Another critical factor on which they reported was that healthcare professionals were unable to care for teenagers and young adults and were therefore unable to support them through the cancer journey. This had a negative impact on the overall cancer experience and heightened their fear and distress about the diagnosis and any further communication from the healthcare team (Hedström et al., 2004; Kyngäs et al., 2001).

In addition to these studies, Kelly et al. (2004) set out to provide further insight into an adolescent cancer unit in England with 10 YP aged 13 to 22. Kelly et al. (2004) used an ethnographic approach to capture the experiences of YP on such a specialist unit and discusses the impact a diagnosis can have on the young person's life, that of their family and the healthcare professional. This paper was particularly pertinent to the UK, where specialist care has been provided for YP with cancer since the early 1990s. The study found that when a diagnosis is given, support from the family is essential, and the healthcare professional is necessary in order to try and work through the diagnosis and move forward within the cancer journey. As one young participant expressed *"I don't want to tell everybody, just some people and then I don't want to talk about it"*. This quote highlights the impact of a cancer diagnosis and that YP often need time to process this and be

supported to work through likely implications of the diagnosis. It was also interesting that the YP were selective of the people they wanted to interact with during this period of their lives. It was also common for YP to reject the initial diagnosis and fail to understand that this disease was now part of their life. The findings from this paper were significant when considering how a diagnosis should be delivered to the patient and by whom.

Similar to Kelly et al. (2004) a further study by Wicks & Mitchell (2010) involving semi-structured interviews with 10 YP, aged 16 to 22 in New Zealand also found that there was a clear need for effective communication especially at the time of diagnosis. Any ongoing psychological support and service delivery needed to be flexible around the specific requirements of the patient. While receiving a cancer diagnosis was reported as mostly negative, the YP reported that having this information communicated to them by a trained and experienced healthcare professional with a positive attitude supported them both emotionally and psychologically. Both these studies have highlighted the need for effective communication at the time of diagnosis, which can lessen the impact of the cancer diagnosis.

Much of the literature to date clearly suggests that how the initial diagnosis is delivered can have a profound impact on the overall cancer journey experience from that point forward (Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Kumar & Schapira, 2013; Miedema et al., 2006; Stegenga & Ward-Smith, 2009; Woodgate, 2006; Wicks & Mitchell, 2010). The diagnostic period was described as traumatic, and life-changing, and had an overall effect on YP's lives. It was important to consider how this information is delivered, where it is given and by whom. The literature suggests that in order to provide effective communication, especially around diagnosis, this should be given by healthcare professionals who know and understand this patient group. The healthcare professional must also be someone who knows the young person and their family. As most of these studies were international, apart from two which were UK based (Gibson et al., 2013; Kelly et al., 2004), the models of care for YP were different across the globe. Most YP and their families felt that their lives had been turned upside down and would never be

the same again, and required support both psychologically and emotionally to cope with this experience and determine how best to move forward with their lives.

2.6.2 Delay in Diagnosis

A delay in diagnosis from the first symptoms was evident in two of the studies (Gibson et al., 2013; Miedema et al., 2006). This was seen as just as crucial to the cancer journey experience as the impact of the diagnosis. Gibson et al. (2013) narrative study involved 24 YP between the ages of 16 to 24 in England who told their stories about physical pain and alterations to their bodies. These YP did not connect these symptoms to anything being wrong, nor did they see the need to visit their General Practitioner (GP). For example, as one young person commented: "*I thought I had just twisted it at a party*" ... (it being his leg) (Gibson et al., 2013 p.2587). However, this study reported that the experience of cancer can be worsened where there is diagnostic delay by the young person, their family or healthcare professional (Gibson et al., 2013).

The Miedema et al. (2006) study interviewed 15 YP aged between 20 to 43 in New Brunswick, a province in Canada. Although the authors had one patient with melanoma in the study, their unique experiences were not evidenced by the study as it is not discussed in the paper. Both Gibson et al. (2013) and Miedema et al. (2006) found that the young person's age and stage of development appeared to contribute to delays in both the young person and the physician's inaction who did not always act on the seriousness of the health concern. For the young person, they did not understand the seriousness of symptoms, and it had not entered their mind that they would have 'cancer'. For those physicians who did not see many cases of cancer in YP, this lack of experience often meant that no prompt action was taken.

These studies illustrated that young adults being diagnosed with cancer need time to process this information and that the diagnosis is clearly and professionally communicated by healthcare professionals effectively and articulately, with the family present (Gibson et al., 2013, Miedema et al., 2006). The experience of a cancer diagnosis was the first step in the overall cancer journey and participants

were able to describe this vividly in the papers included within this sub-theme. The impact on the young person and those close to them is evident and that they require support. Both the young person and the physician need to be aware and recognise the symptoms presented and act on these, whether serious or not. This was an important consideration within the overall cancer experience if delays to diagnosis and treatment are to be avoided.

2.6.3 Family and Friends

Five studies highlighted that YP who are experiencing a diagnosis of cancer need their family and friends to support them through the cancer journey (Hokkanen et al., 2004; Kelly et al., 2004; Kumar & Schapira, 2013; Stegenga & Ward-Smith, 2009; Woodgate, 2006). Within most of the five studies, there was an emphasis on maintaining normal family routines, while recognising the impact that cancer had on family and peer relationships. The descriptive study by Hokkanen et al. (2004) which involved 20 YP, aged 13 to 18 years in Finland, explored what YP's experience of cancer was and how this could be made more accessible. They undertook focus groups at a cancer adjustment camp, which was a camp where YP could receive support from other YP with cancer and have fun at the same time, through camp activities. This was an innovative way to collect data from this patient group and was the only study in this review which has collected the data in this way. As discussed in section 2.7.1 Kelly et al. (2004) highlight that the needs of the family, cannot be separated from that of the young person. Both YP and the family value information and support, which can be offered in a more structured way. For example, receiving communication that is clear and concise by a healthcare professional who knows them and in a way that can be understood.

Although similar to Hokkanen et al. (2004) and Kelly et al. (2004), a study by Kumar & Schapira (2013) found that only some YP affected by their cancer received support from family and friends, while others felt isolated by the disease. Kumar & Schapira's (2013) study examined how young adult patients, aged 18 to 30 years in the USA, made sense of their cancer experiences. It was interesting to find that from the 15 YP who were interviewed, many felt they could rely on family and friends to support them while having chemotherapy or with emotional

distress. Others, however, preferred *“to take care of myself than wait for others”* (Kumar & Schapira, 2013 p.1755). For those YP who experienced this, they turned to support groups at the treatment centre for support. YP appeared caught between two worlds; the world of childhood that they are outgrowing and adulthood, a world they are preparing for and aspiring to, but one that they have not yet fully reached. As apparent in this paper, some YP wanted to be independent and care for themselves without involving their families. This study highlighted that, although this experience was different for some, the YP found that they learnt a lot about themselves and how to care for themselves better. This impacted on their ability to take responsibility, especially at a time where a diagnosis is given and how this influenced their lives (Stegenga & Ward-Smith, 2009, Woodgate, 2006). Stegenga & Ward-Smith (2009) discuss the loss of normalcy having been diagnosed with cancer, and that peer support is fundamental to the cancer experience. Adolescence was highlighted here as a dynamic developmental life stage and having the support of family and friends being a vital part of this. This was another study undertaken in the USA, although phenomenology was used to capture the experiences of ten YP aged 10 to 17 on receiving a cancer diagnosis.

Similar to the paper by Stegenga & Ward-Smith (2009), Woodgate (2006) highlights the need for social support during the adolescence phase. This research undertook a longitudinal study interviewing 15 YP, aged 12 to 18 in Canada. This study found that families, special friends (friends whom they had known for a long time and had a special bond with), and healthcare professionals were the three main supportive relationships YP experience within the cancer journey. The family relationship was the most important to them and the one they most relied upon during treatment. The average age of the YP included in this study was younger than some of the other papers. This may have been a factor in the YP requiring support from their family and friends. Some YP relied on family and friends they were close too as it made them feel safe. As one participant reported *‘being there to hold my hand’* (Woodgate, 2006 p127) and *“the only reason I have come through this far is because of them [family and friends]”* (Woodgate, 2006 p127,125). Having the presence of another human being at a time where the young person is afraid supported them. They felt that having the human touch of

someone they could trust and rely upon helped them through the initial diagnosis and the treatment.

Nevertheless, although supportive for some YP, this study also highlighted that family and friends were at times a source of stress for some others who did not have this special bond. This was because the YP experienced feelings of guilt with regards to family members always having to be there for them. Concerning friends, the YP often felt that they had let their friends down as they could not be there for them.

This section focused on the impact of diagnosis, delay in diagnosis and the value of having family and friends. Being diagnosed with cancer can profoundly impact on YP's lives, their families and that of the healthcare professionals who are caring for them. In addition to the diagnosis, family and friends were seen as necessary for some YP who had developed individual bonds and relationships. However, this was not always seen as necessary for those who did not have a strong relationship with their family or friends. The ability of the young person to take individual responsibility for their healthcare was evident, although this is partly dependent upon the relationship and the age and stage of the young person. Healthcare professionals need to consider these findings when addressing the full care requirements and the needs of the individual patient and that of their family or friends. The following section explores YP's experiences of cancer, in particular, the uncertainty about their life and their future.

2.7 Uncertainty – Holding on to Life

The experience of cancer can often occur at a time when YP are in the process of developing their early adult life plans, transitioning from being a child to teenager and from teenager to young adult (Fern et al., 2013ab). Seven studies discuss that a cancer diagnosis can bring uncertainty and is often associated with hope, fear, and loss of self (Al Omari & Wynaden 2014; Al Omari et al., 2017; Hokkanen et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Wu, Chin, Hasse & Chen, 2009; Zebrack et al., 2014). During this period, YP often found themselves trying to hold on to the life they had imagined. As the disease progresses beyond diagnosis,

and the impact of their treatment grows, YP experience physical, emotional and psychological change, often leading to hope, fear and a loss of self. Cancer brought many challenges which were out of their control.

Nevertheless, having hope provided YP with a way to cope with cancer itself and allowed them to live their lives. This theme has been divided into two sub-themes, but as shown in Figure 2.5, they are interrelated in the overall cancer experience. These subthemes are hope and fear and loss of self.

2.7.1 Hope and Fear

The theme of hope and fear was present in seven of the studies. Young adults experienced fear of the unknown which was mainly due to feeling afraid of having cancer and not being able to cope with this (Al Omari & Wynaden, 2014; Al Omari et al., 2017; Hokkanen et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Wu et al., 2009; Zebrack et al., 2014). These international studies were mainly concerned with young adults' experiences concerning hope which helped them to cope with their fears and enhanced their ability to cope with living with their cancer and treatment. Nevertheless, what was reported in these papers is that YP were not prepared for the treatment or the side effects. Some began to realise that they may even die sooner than they had previously expected and this preoccupied their thoughts, as one young participant expressed *“the idea of death became dominant in my life, cancer is a killer”* (Al Omari & Wynaden, 2014 p 4). These feelings were all-consuming and the fear of being alone and uncertainty about their future and became the main focus of their experience. Two of the studies by Al Omari & Wynaden (2014) and Al Omari et al. (2017) involved 10 to 14 young adults aged between 13 and 18. These studies were the only papers within this review that have both used IPA to explore the experiences of YP being treated for cancer within one of two specialist hospitals in Jordan. Interestingly, the studies were similar, although the 2017 study discusses the coping strategies, whereas the other 2014 study focused on psychological experiences.

One of the coping strategies, 'strengthening spiritual convictions', by Al Omari, et al. (2017) was that YP were Muslim and had a strong belief in Islam and adapted

these rituals to their daily life with cancer. This allowed these YP hope through their faith in that Allah (God) would help cure them of their cancer and support their suffering. This experience of coping through a belief in God is evident within two other studies (Kyngäs et al., 2001; Zebrack et al., 2014). Although Kyngäs et al. (2001) paper included AYAs who had endured > 5 years with cancer, the rationale was not initially apparent, so this paper was included to avoid missing any fundamental research. Other studies identified that prior to the confirmation of diagnosis YP need to have attained effective coping strategies in order to have gained an overall positive experience of cancer (Hokkanen et al., 2004; Kelly et al., 2004; Wu et al., 2009). Understanding YP's coping mechanisms can support the experiences they encounter. In a study by Wu et al. (2009), they interviewed ten YP aged between 12 to 18 in one paediatric haematology/oncology ward. Within their study, although YP experienced loss of confidence and became fearful, they also worked hard to rebuild a sense of hope, which would inevitably help them cope. As one young boy aged 12 expressed *"I could not do what I wanted to do, but I had my life"* (Wu et al., 2009 p2362). Key findings from this study were comparable to other studies by Woodgate (2005, 2006) who discussed YPs' need for psychosocial support. Young people were grateful and happy to be alive, and that part of the recovery from the treatment and cancer meant a new beginning for them, even though they would ultimately be on a different path from the one that had previously been on (Hokkanen et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001).

2.7.2 Loss of Self

Eight studies highlighted how YP experience a sense of loss of self as their bodies dramatically changed from the chemotherapy, radiotherapy and surgery (Al Omari & Wynaden 2014; Al Omari et al., 2017; Kelly et al., 2004; Kumar & Schapira 2013; Stegenga & Ward-Smith 2009; Woodgate, 2005; Wicks & Mitchell, 2010; Zebrack et al., 2014). Within the cancer experience, YP reported that they often lost sight of themselves, physically their bodies changed and they no longer recognised the person they had become. These studies found that having cancer and the treatment which followed, affected their lives. For example, having the treatment meant that their hair would fall out, and they would become unrecognisable. The

loss of their hair affected body image and confidence for many females and being 'bald'. As one young participant explained, "*I am a girl, and I like my hair, without my hair, my friends won't see me*" while another expressed "*When I lose my hair completely, I will cover my head*" (Al Omari & Wynaden, 2017 p37, 38). These quotes highlight how the treatment can affect the overall experience and loss of self. This was interesting as Muslim women often have their head covered but do have the hijab off when with their female friends and husband/s. Although the loss of hair was an issue, loss of a body part (breast) or limb through amputation also had a dramatic effect on the cancer experience and loss of self. Body image plays a vital role here and was related to the young person's loss of themselves, the person they were to the person they had become. Loss of a limb impacted powerfully on the YP but also the family. Both felt that this was the hardest part of the cancer journey experience and having to adapt to a new life with often restricted mobility. This loss seemed to symbolise the destruction that cancer brings and the need to adapt to the new life (Kelly et al., 2004; Kumar & Schapira, 2013).

These physical changes to self also affected the YP psychologically. The concept of loss of self was related to the age group. This loss of self also connects to their identity, which was essential within YP as they transition from being a child to a YP, as discussed in Chapter 1. Within this period of transition, comes change and was often seen as the altered state of self (Kelly et al., 2004; Kumar & Schapira, 2013; Stegenga & Ward-Smith, 2009; Woodgate, 2005; Wicks & Mitchell, 2010; Zebrack et al., 2014). Another study by Zebrack et al. (2014) utilised an open-ended survey questionnaire to collect data from adolescents and young adults (AYAs) aged from 15 to 39 years in the USA. The open-ended survey helped the AYAs describe their experiences with the care they had received. Again, none of the 296 participants who undertook the survey had a diagnosis of MM. This was surprising considering the large sample size in this study and that MM is on the increase in the USA. Struggles were evident within this patient population, especially around efforts to establish a sense of self and maintain a sense of normalcy in their lives. From the sample, n=120 reported that "*cancer sucks*" and was very disruptive to their lives (Zebrack et al., 2014 p.5). This, in return, had an impact on their lives, emotionally, psychologically and physically. Several

indicated that they had lost jobs, lost friends, lost hair, lost motivation due to lack of energy and had struggled with alcohol and drugs. In essence, it was the loss of different aspects of their life that shaped the loss of sense of self. As this study sample has included an older age group, the loss of self may be different than in any of the other studies.

The impact of cancer on the YP and their family has been emphasised in this section, with feelings of uncertainty being prominent within the cancer experience. With this uncertainty about the future, hope for recovery and life itself, and that the fear of having cancer subsides as they move through the cancer journey experience itself. Alongside this were the loss of self once the treatment commences and their physical and emotional state changes. This experience often occurred as they received treatment or surgery, which altered their bodies in ways that changed them. Participants felt that this body change affected the way they felt because of the way they now looked. Concerns about their body image made them feel anxious, less confident and worried about relationships with other people. The following section discusses the gaps in the care delivery; physical, psychological and emotional.

2.8 Gaps in the Care Delivery

Within nine of the studies there were certain aspects of the care delivery that were absent from the overall cancer experience, from the YP perspective (Farjou et al., 2013; Fern et al., 2013b; Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kelly et al., 2004; Kumar & Schapira 2013; Olsson et al., 2015; Wicks & Mitchell, 2010; Zebrack et al., 2014). Being cared for by knowledgeable and experienced healthcare professionals, was critical to the YP and their families, along with the care environment. Within this review, not all YP were cared for within a specialist young adult cancer unit; most were cared for within paediatric or adult wards. It was also clear that YP wanted healthcare professionals to discuss cancer with them rather than their parents or families and for this to be done in a clear and meaningful way that was appropriate for their age and stage of development.

2.8.1 Experience of Healthcare Delivery

The delivery of high quality evidence-based care, by healthcare professionals who are knowledgeable and experienced within the cancer speciality and the immediate and long term implications a cancer diagnosis brings, was a fundamental requirement to the cancer journey experience (Farjou et al., 2013; Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kumar & Schapira 2013; Kelly et al., 2004; Kumar & Schapira 2013; Olsson et al., 2015; Stegenga & Ward-Smith 2009; Zebrack et al., 2014). These ten studies provide the need for information and support, leading up to and following a diagnosis of cancer. For example, YP reported that healthcare professional's attitudes and the way they communicated were often inappropriate. YP commented on how the Oncologist Consultants were quite stern *"it's like talking to a piece of cement"* (Kumar & Schapira, 2013 p1756) and did not address them directly *"I wish people talked to me rather than my parents"* (Farjou et al., 2013 p 725). Both papers identified the importance of the delivery of communication by appropriately educated and trained staff which supported them in developing a trusting relationship with the specialist multidisciplinary team. According to other studies by Gibson et al. (2013) and Stegenga & Ward-Smith (2009) who support these findings, clear and focused information, education and advice should also be made available regarding all aspects of their care, such as diagnosis, chemotherapy, the side effects and what YP themselves choose to be involved in.

One study, in particular, highlighted privatised healthcare, which was an issue for some (Zebrack et al., 2014). This study from the USA found that AYAs who received a cancer diagnosis and then went on to have treatment worried about their future and the financial implications due to unemployment or inadequate health insurance. Cancer often impacted on their employment and on the ability to work, which in return affected the cancer experience. YP worried about this and what their futures would hold once they began and had completed treatment. The lack of a universal healthcare system, as present in the UK, was problematic and worrying for the YP. This has been discussed in Chapter 1 under models of care. Overall AYAs within a privatised healthcare system were unable to integrate the cancer journey into their daily lives, nor did they have the insurance or finances to

support them through this journey. This was very distressing for most of the YP, and they sought solace through adopting coping strategies such as self-belief in 'getting better' which in return gave them hope (Kyngäs et al., 2001; Zebrack et al., 2014).

2.8.2 Age-appropriate Specialist Care

There is a tendency to view the ideal treatment and care experience as arising out of specialist services that are age-appropriate (Lea et al., 2018; NICE, 2006). This however, was not always readily available for all YP with cancer across the globe due to different healthcare systems and resources (Farjou et al., 2013; Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kelly et al., 2004; Miedema et al., 2006; Olsson et al., 2015; Wicks & Mitchell, 2010; Zebrack et al., 2014). Olsson et al. (2015) and Gibson et al. (2013) research focused on what YP experience in their treatment for cancer and what they require to support them through their journey.

Olsson et al. (2015) paper specifically explored the experiences of teenagers and YP treated for cancer in Sweden. This study was undertaken in both child and adult hospitals as there are no young adult cancer units within Sweden. The focus was also within acute hospitals as opposed to community settings. The study included 44 participants, aged 15 to 29, through focus group participation. What is interesting regarding this paper was that the authors have separated the YP into two focus groups, one for those aged 14 to 18 years and a second for those between 19 and 29 years. The 14 to 18 years were treated within paediatric services, and the older age group were treated within the adult services. YP had a solid tumour or eukaemia, and none had MM. However, this study highlighted that YP required an age-appropriate environment which supported their physical and social needs. As one young participant expressed *"there are only old peopleso why was I there?"* (participant 20 years) and *"now we shall do some painting, and only the small children came out of the room, the teenagers stayed in their rooms"* (participant 16 years) (Olsson et al., 2015 p 578). The study also found that these specific needs of having an age-appropriate environment and psychosocial support varied over time and throughout the cancer journey and

were unique to each person. It was clear from this study that these needs were not being met. They wanted the hospital interior to be different and equipped for YP and to be cared for within an area where there were people of their own age.

A further study by Farjou et al. (2013) set out to understand the healthcare experiences of 200 YP through an open-ended questionnaire, within three paediatric hospitals in Canada. The YP were aged between 12 to 20, with 79 being actively treated and 121 were off treatment and being followed up regularly. This study found that the environment was important, especially the social interaction that teenagers require, and an environment that is comfortable for them and their families. It was clear from the literature that this type of environment would support their interaction with their peers. Again, unsurprisingly, this paper highlighted that not all countries provided care for teenagers or YP. Many are still being cared for within either the paediatric or adult environment.

This theme demonstrated that there are gaps in the care delivery for YP with cancer and their families. Cancer care needs to be delivered in appropriate environments which are conducive to the age and stage of the young individual. The care delivery was necessary, and it was highlighted that this should be provided by knowledgeable and competent healthcare professionals and that specialist care is available for all YP.

2.9 Summary and Conclusions

The literature search was updated during September 2019 and revealed a further 13 papers concerned with YP living with MM, and an additional 65 papers exploring how YP were living with cancer, but none met the inclusion/exclusion criteria. Consequently, these papers were categorised as irrelevant to my study because the majority were quantitative studies focusing on the needs of an adult population. There were two studies retrieved concerning adults with experiences of MM but neither included the family/significant other nor did these studies use an IPA approach (Bird et al., 2015 & Hajdarevic et al., 2014), or meet the inclusion criteria for my research. Other studies have selected more general MM research in the TYA population and have chosen to work within the quantitative

methodological paradigm or a mixture of both quantitative and qualitative approaches (Hubbard et al., 2018). Most of the literature regarding YPs experiences were concerned with all types of cancers without focusing on singular diseases. Some of the papers in the literature review were concerned with the family (n=2) however, this was not common, and none included the family/significant other.

It is clear from existing literature that there was no international or national research focusing on the experiences of YP living with an MM diagnosis, nor any studies utilising an IPA methodology. This can also be said for the experiences of the families /significant other who share the journey with the young person. This review has identified the gap in knowledge regarding the dynamic relationship between the YP their family/significant other and has provided an insight into the dearth of knowledge in one specific type of cancer. Current research has tended to focus on the experiences of YP living with other types of cancer, such as Leukaemia and Lymphoma, to the exclusion of MM. As the family/carer is vital within the cancer journey, they were also included.

The Taylor et al. (2013) meta-synthesis was included to support the second literature review regarding YPs experiences of cancer. However, none of these studies included any YP with MM, nor did they include the family/significant other. The Taylor et al. (2013) review differed in that their inclusion/exclusion criteria included both types of research methodology, although they only used the qualitative material to develop their conceptual model. This model depicts the mediators and consequences of cancer care that impact on YPs quality of life after a diagnosis of cancer has been received. It was interesting to see that the model does include social support. However, the family/significant other were not central to this support nor seen as being important in the YP cancer journey and there was no consideration given to the dynamic interrelationships.

A more extensive review of the literature of young adult's experiences of cancer found that there were critical aspects to the cancer experience: Theme 1 – cancer diagnosis, Theme 2 - the uncertainty this brought to their lives and the feeling that their lives were put on hold and Theme 3 - the gaps within the care delivery. This

review found 18 qualitative research papers focusing on YPs experiences of cancer. However, only two of the studies used IPA and four used phenomenologies to give the studies the depth and meaning of the lived experience. There was also a limited amount of research that involved both the young person with cancer and their families. Only one of the 18 papers included the family (and given the emphasis from the review on the importance of family and friends, this appears to be a significant omission from the research (Kelly et al., 2004).

Much of the literature revealed that a cancer diagnosis has an impact on the overall experience of one's life from that point onwards. (Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Kumar & Schapira 2013; Stegenga & Ward-Smith, 2009; Woodgate, 2006; Wicks & Mitchell, 2010). A key finding was that these studies all present the experiences of being diagnosed with cancer but the actual word 'cancer' was rarely used within the healthcare setting. It was not clear from the literature why the word 'cancer' was not used by the healthcare professional but needs consideration in how a cancer diagnosis is given, where and by whom. It was interesting in the paper by Miedema et al. (2006) that the delay in diagnosis may not affect the health outcome, which was contradictory to current evidence, as delay in diagnosis can be detrimental to the overall disease process, especially MM, and early intervention is essential (Gibson et al., 2013). It did, however, impact on the experience both psychologically and emotionally (Miedema et al., 2006). Where YP are treated and cared for and by who needs careful consideration and the approach to how healthcare professionals communicate with YP was fundamental to the cancer experience. It was also suggested that YP and physicians need to be aware of the symptoms presented and be prepared to act on these whether serious or not. This was imperative within the cancer experience and this patient group in particular.

The impact of cancer on the young person has been emphasised throughout the review, and it became clear that YP living with cancer experience uncertainty about their future. With this uncertainty, there was also hope for recovery and life itself. The fear of having cancer, and the reality that death may be pending, did

feature and quickly subsided as they moved through the cancer journey. Alongside this is the loss of themselves once the treatment commences and their physical and emotional state changes (Al Omari & Wynaden, 2014; Al Omari et al., 2017; Kelly et al., 2004; Kumar & Schapira, 2013; Stegenga & Ward-Smith, 2009; Woodgate, 2005; Wicks & Mitchell, 2010; Zebrack et al., 2014).

YP with cancer experience a wide variety of different treatments and care processes and the needs of the family cannot be separated from that of the young person with cancer. Both family and friends were significant others within the cancer experience. There was a tendency to view the ideal treatment and care experience as arising out of age-appropriate specialist services. However, this was not always readily available for all YP with cancer across the globe due to different healthcare systems and resources. Where and how the treatment and care are delivered by competent healthcare professionals, who are knowledgeable about the immediate and long-term implications of cancer therapies, was necessary. This was a fundamental requirement in order that YP and their families can be supported and prepared for whatever lies ahead.

Existing literature documents that YP with different types of cancer experience a variety of care and treatment processes. It is not fully understood what YP and their families/significant other with MM experience, especially at a time in their lives when they are looking forward to what the future holds. More specifically, MM is an under-explored area, particularly in terms of the lived experience.

There was no qualitative research that has focused on YP's experiences of living with MM, or for their families/significant other, and this provided the rationale and justification for my study. Although a rare disease, it is increasing within YP, particularly within Scotland, and healthcare professionals will need to be prepared and equipped on how to care for this specific age group within a relational context. This is important as YP are often still living within the family home or with a loved one or friend/s. As I wanted to explore the experiences of what it meant for YP and their family/significant other living with MM, this novel qualitative approach fitted well with my research aims and questions. Further research on individual

cancers is required to understand the impact they have on YP and their family/significant other and their unique care requirements.

Chapter 3 - Methodology and Methods

3.1 Introduction

This Chapter begins by discussing the rationale and justification for selecting a qualitative IPA approach to explore the experiences of YP and their families/significant other living with MM, as opposed to other methodological approaches. The paradigms and the philosophical theory that supports IPA are discussed along with the epistemological and ontological underpinnings, and my own positionality and reflexivity within the selected methodology are presented. Following the methodology sections, the methods I used to conduct the research are also discussed.

3.2 Research Focus

In Chapter 2, the critical narrative review and discussion of the available literature confirmed the paucity of specific research concerned with the experiences of YP living with MM, and this study closes the identified gap. Moving beyond the YP experiences alone, I have gone further in considering the family/significant other within this journey and how this disease had affected the YP as well as their family/significant other. As the second literature review concerned the experiences of all cancers, I wanted to specifically research one type of cancer in considerable depth to determine if there were any other gaps when considering this population group as opposed to research clusters of many cancer types. Anecdotal evidence indicated that YP experiencing an MM journey were different from other YP with different types of cancers. In addition, I wanted to utilise a novel methodology that understands how these YP, and those that matter to them, make meaning from their experiences in real depth.

In identifying and selecting an appropriate methodology, it was essential to consider the core research aims and the associated questions that would deliver the required richness and deep insights. As Newell & Burnard (2006) suggest, it is essential to avoid methodological choices that reflect the preferences of the

researcher and focus on suitable methodologies to answer the research questions noted in Table 3.1.

Table 3.1: Research Aim and Questions

Research Aim and Questions	
Aim:	Explore the experiences of young people and their family/significant other living with MM within Scotland.
Question 1	What are the experiences of young people and their family/significant other living with malignant melanoma?
Question 2	What are young people and family/significant other experiences of the support and care they require or need?
Question 3	What further support or improvements in care do young people and family/significant other identify?

In contrast to positivism, where the researcher relies specifically on scientific evidence, is the constructivist approach, also known as the naturalistic inquiry (Guba & Lincoln, 1994) which proposes multiple realities that are dependent upon context. This approach is steeped in subjectivity and is associated with the qualitative research methodology. Qualitative studies are designed to collect rich data in a non-threatening way and ensure credibility and trustworthiness in attempting to answer questions around individual and group experiences and perceptions (Parahoo, 2014; 2006). The qualitative researcher endeavours to tell the story of an individual or group's experiences or perceptions in their own words. Qualitative research focuses on narrative compared to quantitative research, which focuses on data, numbers and facts (Guba & Lincoln, 1994). Qualitative research logic can be challenging for those researchers more accustomed to the alternative deductive approach. Qualitative research employs an inductive approach where the researcher first collects data and then attempts to derive explanations from that data. Consequently, qualitative research tends to be more exploratory, seeking to provide insight into how individuals and groups understand their world (Polit & Beck, 2010). Various qualitative designs were critically considered against the research questions and in order to find the most appropriate approach.

3.3 Research Paradigms

All researchers have their own individual views on what constitutes truth, knowledge and understanding. It is these views that often guide and inform how researchers frame the world around them. This is known as a paradigm and was defined by Schwandt (2001, p183-184) as a “shared world view that represents the beliefs and values in a discipline and that guides how problems are solved.”

Research paradigms can be defined as sets of beliefs, conceptions and values concerning the nature of reality and knowledge construction held by a discipline, which inform the priorities for research and process of inquiry (Kuhn, 1970). Currently, within healthcare research, the leading paradigms may be considered as a positivist, constructivist/interpretive and critical social theory, the foundation respectively for quantitative and qualitative approaches (Parahoo, 2014).

In selecting the most appropriate research paradigm to answer the research aims and questions, both quantitative and qualitative paradigms were considered. The quantitative research approach is heavily influenced by the traditional sciences and aims to objectively examine and map the relationships between known variables through empirical measurement and statistical analysis (Parahoo, 2014; 2006). In contrast to the quantitative approach, qualitative research studies are popular, have gained widespread acceptance within healthcare over the years and are designed to ensure trustworthiness and permit rich data to be collected in a non-threatening way (Bryman, 2008). It was clear that a qualitative research approach would be more suited to answering research questions that focused on capturing and interpreting personal experiences. This conclusion was supported by the literature review in Chapter 2, which revealed that research studies exploring the experiences and personal impact of a major disease such as MM can bring mainly relied on the qualitative research paradigm with their emphasis on subjective experiences. According to Guba & Lincoln (1994), research paradigms can be characterised through their epistemological and ontological stance.

3.4 Research Methodologies Considered

As discussed in Section 3.2, there is a knowledge gap in the literature around the experiences of YP and their family/significant other living with MM. Consequently, the following research designs were considered – mixed methods, case study and grounded theory. Mixed methodology has been criticised by some researchers who argue that the paradigms are often grounded in incompatible epistemological and ontological principles (Rolfe 2006, Silverman, 2006). The principal concern of epistemology has tended to be the philosophical exploration of propositional knowledge (Meleis, 1992) and considers addressing questions such as 'how do I know what I know, and what counts as proof of what we know?' Ontology, however, explores the essence of things helping to grapple with the fundamentals of our questions, for example, 'what is nursing?'. Nevertheless, Bryman (2008) acknowledges this but suggests that quantitative and qualitative approaches can complement one another as they can deliver different types of knowledge to identify the evidence that the researcher was seeking to find. A mixed methodology, combining quantitative and qualitative methodologies, was considered for the research questions as this methodology has gained greater prominence and academic acknowledgement (Creswell, 2009).

3.4.1 Mixed Methods

In considering the mixed methodology approach, a survey design questionnaire with open and closed questions to investigate the participants' experiences of living with MM was discussed. However, this approach would lead to copious amounts of data which would have been advantageous to the study but would not have addressed the initial research questions and the focus on people's experiences with MM (Bryman 2008; Parahoo, 2014). Survey design is a popular method with social scientists, sociologists and increasingly amongst nursing research. This approach, according to Parahoo (2014; 2006), is cost and resource-effective as opposed to the qualitative interview. The use of a survey design was ultimately rejected due to the research questions and the small number of participants diagnosed with MM in Scotland, approximately 14 per year. Besides, the quantitative methodology predominantly utilises a deductive strategy

and the testing or confirming of theories, which incorporate practices of positivism and quantification (Polit & Beck, 2010). It would be difficult to quantify and measure the participants experience through closed and open-ended questions, as there may be too many variables to control (Parahoo, 2006). As such, the mixed methodology was disregarded. Nonetheless, as my research aims and questions finally evolved into 'exploring the experiences of YP living with MM and their family/significant other' this methodology approach was considered unsuitable for this study.

3.4.2 Case Study

The case study methodology is useful in helping the researcher explore the data in some detail within a specific context, most commonly restricted to a limited number of participants or small geographical location. Fundamentally, the case study approach permits the investigation and exploration of the current real-life phenomenon, such as transition, through the detailed analysis of a limited number of contextual events or conditions, and their relationships (Parahoo, 2014). Yin (1984 p23) describes the case study research method "as an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not evident; and in which multiple sources of evidence are used." The case study approach was disregarded due to the research focus on the YPs experience of living with MM and not investigating a contemporary real-life phenomenon. This real-life phenomenon would have been challenging to capture through a case study unless the specific methodology was adapted to follow an IPA approach. An example of this is seen within a single case study by Eatough & Shaw (2019) who present the understanding of the lifeworld for someone living with Parkinson's disease. Due to the nature of my research aims, questions and interest, I was keen to include YP and their family/significant other from across Scotland rather than focusing on a single case study.

3.4.3 Grounded Theory

Grounded theory was also considered to address the research questions. Grounded theory focuses on social processes and structures and was seen as a valid consideration. This approach is grounded in data collected from the individual participants, either through interview or by observation within the participant's environment (Silverman, 2006). The grounded theory design was originally developed in the early 1960s by American sociologists Glaser & Strauss (1967), and later by Strauss & Corbin (1997). The philosophical basis predominantly is a symbolic interaction and pragmatism, utilised to investigate and explain human experiences, actions and interactions within the context of social-psychological processes. The specific types of data discovered, generated or constructed depends on the grounded theory tradition followed by the researcher. It can be difficult to confidently predict the direction and duration of the study at the outset, due to the theoretical sampling and the process of constant comparison in data collection and analysis until theoretical saturation is achieved (Charmaz, 2000). Time limitations precluded the use of a grounded theory approach, and as my study was to consider the individual experiences rather than wishing to generate models of theories to explain the phenomena, this design was disregarded.

3.5 Phenomenology

My earlier Masters Level research (McInally, Masters & Key, 2012) involved conducting a phenomenological study informed by critical theory, which provided a strong foundation for conducting qualitative research within the phenomenological paradigm. The experience of planning, designing and implementing this research programme positively shaped my knowledge and understanding of the value and robustness of the phenomenology methodology and for the type of research questions, it is suitable to address.

Phenomenology is a philosophical approach to the study of experience. In life, phenomenology is concerned with the experience of being human and what matters along with what constitutes the world in which lived (Smith, Flowers &

Larkin, 2009). Phenomenological enquiry has two distinct approaches; descriptive and interpretative phenomenology (Smith et al., 2009). Interpretative phenomenology analysis has foundations in both and phenomenology is, therefore, the underpinning of IPA (Peat, Rodriguez & Smith, 2019). Healthcare professional researchers pursuing a qualitative approach to their research have gravitated towards different qualitative designs, including phenomenological methodology, perhaps to reflect the perceived holistic nature of their work.

Descriptive phenomenology aims to describe the lived experience without giving meaning (Smith et al., 2009). The principal founder of phenomenology, Edmund Husserl (1859 – 1938), and the originator of descriptive phenomenology suggested that during data collection and analysis the researcher should 'bracket' or leave aside previous knowledge and investment to enable the phenomena to be illuminated as experienced. Husserl wanted to grasp the essence that makes possible an experience of any kind. Originally a mathematician, Husserl became disenchanted and disillusioned with the natural sciences as a means of studying human experience (McConnell-Henry, Chapman & Francis, 2009). Husserl opposed the view that empirical science was the sovereign arbiter of truth and saw phenomenology as a way of returning to and exploring the reality of life and living, of going 'back to the things themselves' (Tuohy, Cooney, Dowling, Murphy & Sixsmith, 2013). Crotty (1996) and Paley (2014) have criticised researchers for the use of Husserl phenomenology on the basis that many researchers have misunderstood Husserl's original intentions. This position is based on the belief that very few researchers have directly referenced the original research conclusions of Husserl. Given that Husserl's writing is in his native German, it is easy to understand why researchers have not fully accessed his research, even though his work has been translated into English.

Husserl introduced the concept of the 'lifeworld', meaning the world as it is immediately experienced (Wilson, 2018), and claimed that the lifeworld was not readily accessible, as it constituted that which is taken for granted and those things which are common sense (and therefore go largely unnoticed) (Koch, 1995). Study of the lifeworld explores what an experience is like 'pre-reflectively', focusing on that which is experienced in the consciousness of the individual (Eatough & Shaw

2019; Smith et al., 2009). It is prudent to explore some of the critical concepts of descriptive phenomenology, and how this has influenced my research, as a deeper understanding can serve to help illuminate the contrasting hermeneutic paradigm of Heidegger, and discussion of the concept of bracketing provides a rationale for the rejection of pure descriptive phenomenology in this study (Wilson, 2018).

The descriptive phenomenology concept was later challenged by Martin Heidegger (1889 - 1976), Merleau-Ponty (1908 – 1961) and Gadamer (1976) who suggested that to describe a lived experience fully, and an interpretative phenomenology researcher cannot extract themselves from the research and interpretations are made from our perceptions. The interpretation of an individual's 'meaning-making' is considered in light of the researcher's perspective, at that specific time. According to Heidegger, researchers observe and empathise but view phenomena from their own perspective of being in the world; and the narrative is developed through interpretation (Peat et al., 2019). Heidegger's seminal work *Sein und Zeit* (Being and Time) illustrates how he moved radically away from Husserl's phenomenological approach (Earle, 2010; Heidegger, 1962). The term hermeneutic phenomenology is therefore attributed to Heidegger and is influenced by an ontological perspective concerned with the nature of "being in the world" or "Dasein" (Heidegger, 1962, p41). The process of bracketing provides epistemological information, rather than ontological, for example, one can know about a life event through description but to truly understand this life event meaning must be derived from this (Smith et al., 2009). Heidegger travelled from the epistemological emphasis of Husserl to an emphasis on the ontological perspective believing the outcome of phenomenological research should be understanding and meaning through interpretation rather than a purely descriptive science (Wilson, 2018). Heidegger disagreed with Husserl and subsequently criticised and rejected this notion of 'bracketing'. Heidegger and other existential phenomenologists (LeVasseur, 2003), believed that understanding is never without presuppositions (Earle, 2010) and that understanding is already there, and cannot, nor should not, be divorced from our thinking.

Heidegger, similar to Gadamer (1976) rejects 'bracketing' by questioning whether preconceptions of the researcher may be truly set aside, through adopting an attitude of openness. Gadamer also acknowledges individuals as historical beings, bringing with them life experiences and beliefs which shape the meaning and understanding of new experiences within their lifeworld (Wilson, 2018). Phenomenology is concerned with an epistemological and ontological position whereby the researcher strives to explore the essence of what the individual feels is real, authentic and important. Researchers accept that each individual have different life experiences and that the truth can often be deceptive and subjective (Denzin & Lincoln, 2005; Rolfe, 2006). As different scholars employed divergent philosophies regarding phenomenology, various strands arose with differing epistemological and ontological perspectives. A phenomenological researcher, therefore, seeks to describe the meaning of the 'lived experiences' for several individuals regarding a certain phenomenon (Van Manen, 1990; Willig, 2011).

When pursuing a phenomenological methodology, researchers must wrestle with a fundamental problem within the approach. Once the research findings are recorded and transcribed the original meanings may be lost or distorted by this process. This is a valid criticism and not one that is easily overcome. As discussed earlier, all researchers view the world around them through their own unique set of individual filters. In attempting to address this issue, some authors have referred to the original German texts to provide further insight and understanding of the approach (Fleming, Gaidys & Robb, 2003). However, Koch (1995, p174) has observed that "wrestling with obscure German texts" is not a primary objective of nursing researchers. Researchers are required to understand the philosophical underpinnings of the methodology to ensure the delivery of robust and accurate research.

It was recognised at the beginning of this study that each participant would have a personal perspective to add, but due to the very nature of the study, there would potentially be common shared experiences (Smith et al., 2009). Conducted to generate knowledge, the study was to be inductive with a focus on what the participants say rather than quantification in the collection and analysis of data, further suggesting the qualitative paradigm and the phenomenological approach

(Bryman, 2008; Bloomberg & Volpe, 2008). In summary, this approach was pivotal in the selection of IPA as the primary research approach, which is rooted within the work of Husserl, Heidegger, and Gadamer, alongside other philosophers' work.

3.5.1 Epistemology and Ontology

At its core, the IPA approach is concerned with an epistemological and ontological position. In IPA we may wish to treat people's experience as a lens for illuminating the broader meaning or consequences of an event or journey such as MM to understand its broader constitution, dynamics, or mechanisms (Larkin, Shaw & Flowers, 2019). A phenomenological researcher looks to accurately describe the meaning of the 'lived experiences' of several individuals regarding a particular phenomenon (Peat et al., 2019; Van Manen, 1990). Throughout the process, the researcher is required to suspend or disconnect their natural attitude, perceptions, beliefs and experiences to ensure objectivity and to fully understand the phenomena as it truly appears, which supports the Husserlian phenomenology.

The epistemology of IPA is built around the interpretative inquiry of the narratives of the individual's lived experiences, and the research questions should focus on the understandings of these experiences and should be exploratory as opposed to explanatory questions (Smith et al., 2009). Considering the epistemological position and how it is defined, some suggest that it relates to the theory and nature of knowledge (Finlay & Ballinger, 2006) with others offering slightly differing definitions. It is proposed that epistemology relates to the claims or assumptions about how it is possible to gain knowledge (Blaikie, 2007) and should be identified with the goals of the research in mind. This ensures that these aims are achieved and demonstrate coherence and rigour in the study. Awareness of these philosophical concepts increases the quality of research and can contribute to the creativity of the researcher.

Ontology is defined as the nature of reality. It explores the essence of things, helping us, for example, to understand the attributes of being a person and shedding some light on the questions we require answers to (Creswell, 2009).

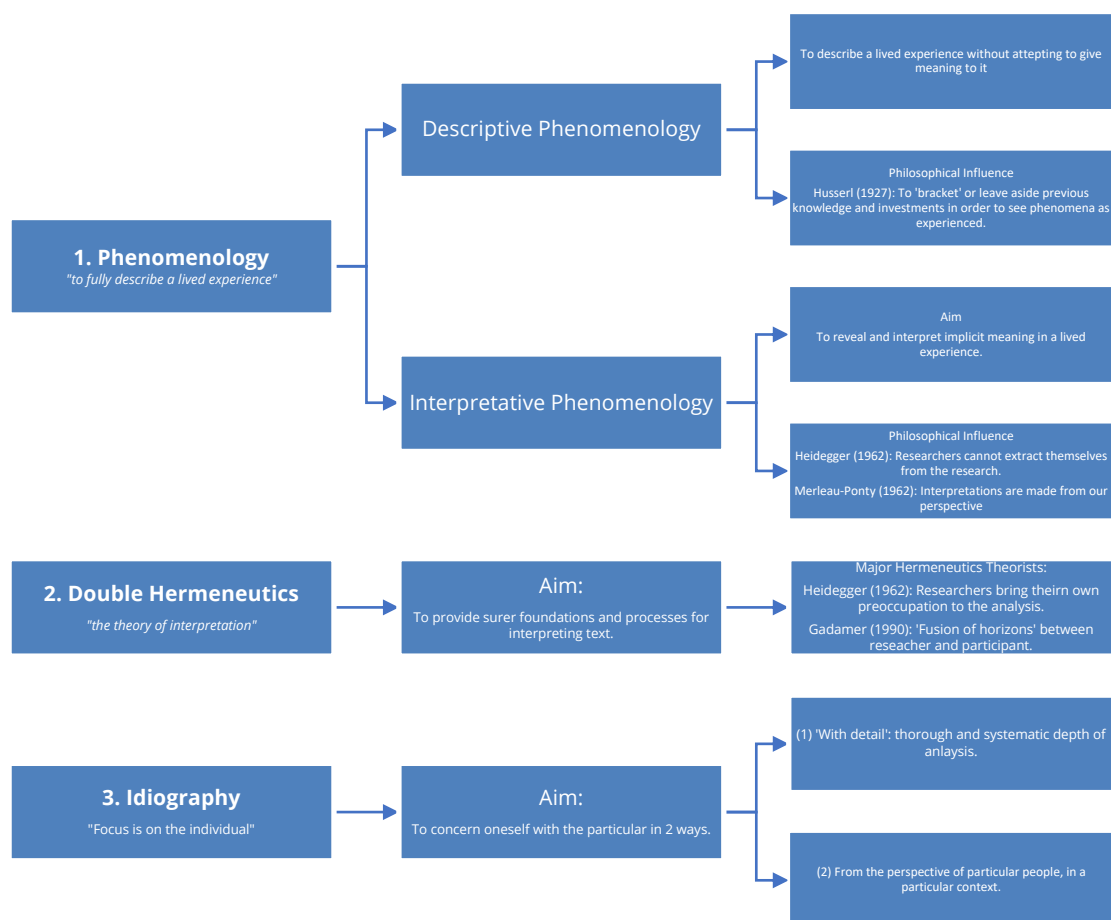
Within the IPA approach and this study, where it is crucial to explore the experiences of living with such a disease and being in the world in which we live, the work by Heidegger also requires to be considered (McConnell-Henry et al., 2009). Part of this reality, however, is different for each person and therefore it must be explicit as to how each phenomenon is viewed by the researcher, acknowledging that many biases and interpretations influence the research. At one end of the ontological continuum sits realism which assumes there is only one reality that is entirely independent of human subjectivity. At the other end of this continuum is relativism where there are multiple realities which are entirely dependent upon human subjectivity and interpretation (Braun & Clarke, 2013). My study aimed to align itself with the constructivist theoretical underpinnings which informed a relativist epistemological approach informed by an IPA methodology which suggests that the lifeworld consists of many individual realities which are influenced by our culture, society and the wider world we live in (Wilson, 2018).

It is important to acknowledge at this point, that participants rely on somatics in that they tell the story of their experiences as they remember it, at the time, through their mind and body (Osborn & Smith, 2006; Smith & Osborn, 2007). For example, when the participants were describing their experiences, they could relate this to what was real and true for them at this time. They could refer to the shock and worry they had experienced in receiving bad news or the pain they had to bear from the surgery. This supports previous philosophers' work including Husserl, Heidegger and Merleau-Ponty.

3.5.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis was originally developed in 1995 by Johnathan Smith as a method to undertake experiential research in psychology, and has gained prominence across health and social sciences as a way to understand and interpret topics which are complex and emotionally laden, such as disease, chronic illness experiences (Peat et al., 2019). In essence, IPA consists of three central tenets - phenomenology, hermeneutics and idiography (Smith et al., 2009) as summarised in Figure 3.1.

Figure 3.1: The Three Influences of IPA



Adapted from: Smith et al. (2009)

In earlier sections within this Chapter, I have tried to provide a deeper understanding of the philosophical and methodological nuances of Phenomenology and IPA (Smith2009). The purpose of this research was to illuminate and steer the research to gain a deeper understanding of the experiences of YPs and family/significant others living with MM.

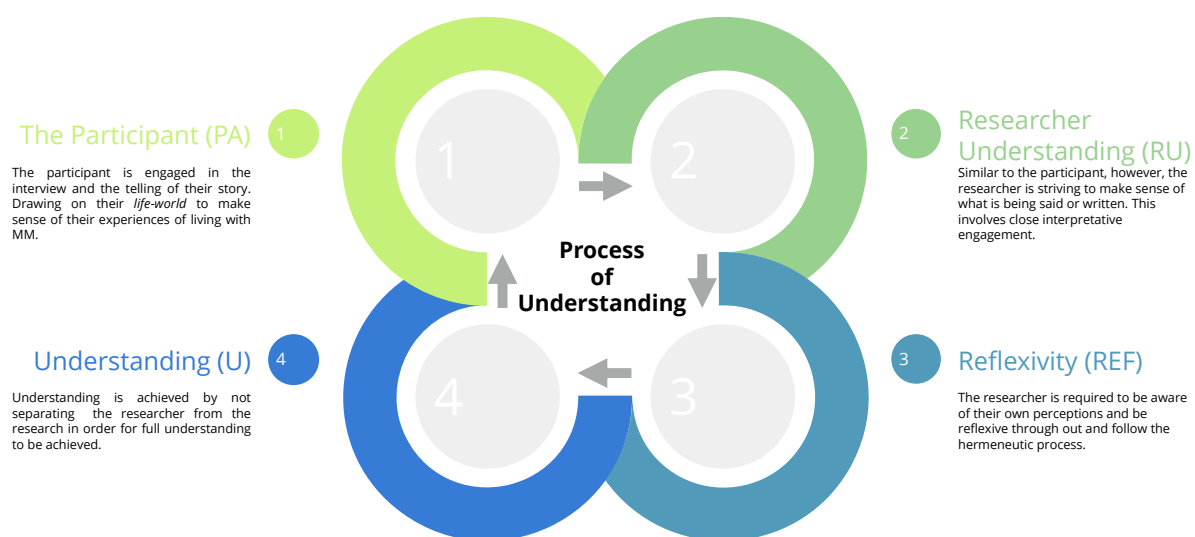
Interpretative Phenomenology Analysis (IPA) aims to uncover what a lived experience means to the individual through a process of in-depth reflective inquiry (Smith et al., 2009). The interpretative phenomenological analysis draws on phenomenological thinking, with the purpose to return 'to the things themselves' (Smith et al., 2009 p168). However, IPA also acknowledges that we are each influenced by the worlds in which we live and the experiences we encounter. Therefore, IPA is an interpretative process between the researcher and

researched, influenced predominantly by Heidegger's interpretive phenomenology, hermeneutics and idiography. Within IPA, it is typical for researchers to select a small homogenous sample to explore the shared perspectives on a single phenomenon of interest (Larkin, Shaw & Flowers, 2019). Undertaking an IPA approach, concerned with the epistemological and ontological theoretical underpinnings supported the aims and objectives of this study. Over time, the theoretical foundations of IPA are likely to be further refined and strengthened (Larkin et al., 2019). Smith et al. (2009), have suggested that the main strength of IPA as a research methodology lies in the detailed description of the interpretative analysis.

3.5.3 Hermeneutics

Following in the footsteps of Husserl, his student Martin Heidegger sought to further develop the underpinnings of the hermeneutics concept with his theory of interpretation. While IPA researchers view the participant as the experiential expert, they acknowledge that experience cannot be revealed. Instead, the process of rich engagement and interpretation involving both the researcher and researched is required for an understanding to be reached (Smith et al., 2009). This can be seen in Figure 3.2.

Figure 3.2: Process of Understanding - PA+RU+REF=U



Adapted from: Smith et al. (2009)

This engagement is commonly referred to as the double hermeneutic approach to analysis, whereby the researcher seeks to make sense of the participants making sense of their world (Wilson, 2018). To allow for this to occur, IPA researchers are required to engage with what is known as the hermeneutic circle. The hermeneutic circle can be thought of as an iterative process involving moving between the smaller units of meaning and the larger units of meaning, or between the parts and the whole of the investigated phenomena or lived experience. Table 3.2 illustrates that each sentence and section of the transcription was subsequently examined to expose meaning and identify the experiences of each participant (Smith et al., 2009).

Table 3.2: The Hermeneutic Circle

The Part	The Whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

It was clear that IPA was the most appropriate approach and directly informed the further development of the research questions, data collection methods and data analysis. Smith et al., (2009) discuss the similarities between IPA and social constructionism as the IPA methodology strives to reveal the lived experiences of the individual and determine the meaning and impact within their own life and that of their family/significant other. Gadamer (1976) argues that when analysing/interpreting the narrative, the researcher is trying to make sense of the text rather than the participant. This supports the work of Heidegger, hermeneutics and the challenges between the interpreter and the interpreted.

3.5.4 Idiographic Approach

The basic principles of IPA feature a hermeneutic and idiographic approach focusing on the particular, rather than the general. This approach demonstrates an understanding of how distinct groups make sense of specific phenomena in a

context (Smith et al., 2009). This IPA approach was necessary from the outset to achieve an “insider’s perspective” (Larkin & Griffiths, 2002, p.284) and to develop a deeper understanding of the lived MM experiences. It is therefore inductive, (by rejecting hypotheses) and the idiographic procedures of IPA help achieve the research aims and answer the questions. The focus of an IPA researcher is on idiographic inquiry, as compared to a nomothetic inquiry. This idiographic commitment has a two-level function. Firstly, the IPA aims to explore in detail the experiences of individual people in particular contexts. Secondly, from a methodological stance, the analysis is detailed and very intensive to present accounts of a small number of participants (Smith, 2017). In the findings, the narrative that is used to represent the whole group must always be traced back to the level of the individual. Larkin et al. (2019) posit that there must always be a balancing act between description and interpretation when conducting an IPA study.

Within this research approach, I strived to be consistent and compatible with the hermeneutic and idiographic approach of IPA. The individual interviews, in contrast to the dyad interviews, presented a new multi-perspective approach that permitted rich data to be collected from both YP and their family/significant other (Larkin et al., 2019). Consequently, IPA can be viewed as idiographic as the individual’s experience and the meaning of that experience is of paramount importance. Researchers utilising the IPA approach endeavour to understand the participants trying to make sense of their world, with detailed analysis involving the linguistic, affective and physical being, which Smith & Osborn (2003, p51; 2007) refer to as the “double hermeneutic”, allowing for deep interpretative analysis at the level of the individual.

3.5.5 Positionality and Reflexivity in IPA

It was clear from the initial planning stages, and from subsequent discussions with my supervisory team that IPA was a research methodology that appealed to me both professionally and personally. The impact of how a cancer diagnosis affects the individual life trajectory and that of their family/significant has always been of particular interest to me. Being a paediatric nurse through training in the early

1990s, family centred care has always been an important consideration for me and is enshrined within the philosophy of Child Health nursing (Darbyshire, 1994; Coyne, et al., 2016; Arnett, 2006).

As identified in the Chapter 2 literature review, there is no national or international research focusing on the experiences of YP living with MM or the impact on the family/significant other. Within the IPA approach, identifying the researcher's positionality and being reflexive is essential, and the two are linked closely to the concept of 'bracketing' and 'hermeneutics' as discussed earlier in this Chapter. Within IPA, bracketing is recognised as not being entirely possible, nor should we want to use it within this methodology (Smith et al., 2009). Being transparent and reflective throughout the research process supported the participant's own narrative and my understandings to ensure that the interpretations were grounded and authentic of the participant's stories. It is important to stress here what the dialogue brings to the text and what the text brings to the researcher (Smith et al., 2009). I acknowledged the inevitability of biases and assumptions when conducting this research and kept a reflexive audio diary throughout. It is suggested that researchers using IPA reflect on how this shapes their research inquiries and, following Gadamer (1976), they aim to engage with them entirely for understanding which ultimately allows for the 'fusion of horizons'. When this fusion occurs, there is an understanding concerning the researcher and the researched (Wilson, 2018).

3.6 Methods

The methods employed within the study are discussed within this Chapter in four parts to explain the analytical journey taken as well as providing a coherent and logical account of the data collection and data interpretation methods in keeping with an IPA approach. Firstly, participant selection and recruitment criteria are discussed, along with the ethical considerations required and ethical approvals pertinent to this study explored. Secondly, the data collection methods are examined in some detail, analysing the congruence to the methodology. Thirdly, a number of the theoretical approaches to qualitative data analysis are examined, before a reasoned argument for the approach used in analysing the data is

presented. The work of Smith et al. (2009) underpins this overall approach. Lastly, the steps taken to ensure credibility and rigour during the analysis process are made explicit following Yardley's (2000) four broad principles for assessing quality in qualitative research thus strengthening the personal trustworthiness of the research. I have followed the guidance of consolidated criteria for reporting qualitative research (COREQ) to build rigour in this section of my thesis (Tong, Sainsbury & Craig, 2007).

3.6.1 Selection of Research Participants

This study focuses on YP who had been newly diagnosed and had lived with MM for less than five years. I wanted to capture the YP's experience in this time rather than living after the treatment and surviving this disease. The family/significant other were also included as they play an essential role within the age group I was considering, and this group had been a notable exclusion from previous research. The proposed small sample size of the study was appropriate to a qualitative IPA methodology to capture and illuminate the lived MM experience.

In Scotland, there are approximately 14 YP between 16 to 24 years of age diagnosed with MM each year. Although this disease is more common in females than males, it was hoped that recruitment of both genders would have been possible comprising three men (n=3) and three (n=3) women (ISD, 2019), six (n=6) family members/significant other. However, as the number of YP diagnosed with this disease is relatively small compared to other cancers, and once they are treated, it is often difficult to follow them through the journey.

3.6.2 Population

The researcher and the Clinical Nurse Specialists (CNSs) confirmed the participant inclusion/exclusion criteria before obtaining consent. The inclusion/exclusion criteria for all participants are outlined in Table 3.3, stating the inclusion/exclusion criteria.

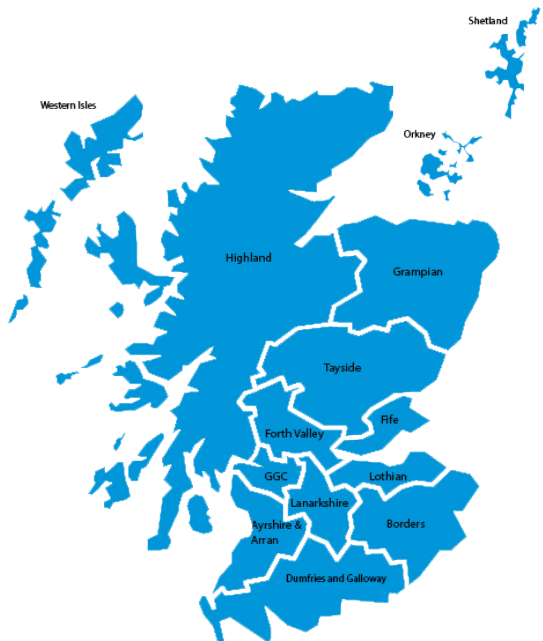
Table 3.3: Inclusion and Exclusion Criteria

Inclusion Criteria:	Exclusion Criteria:
<ul style="list-style-type: none">• Aged 16 to 26 years.• Family members aged 16 to 80 years.• Male or Female.• Malignant Melanoma, Stages 1 to 4.• Live within Scotland.• English speaking.	<ul style="list-style-type: none">• <16 years and >26 years.• Young people with severe cognitive impairment.• All other cancers.• Non-resident in Scotland.• Non-English speaking.

3.6.3 Population Size

The original intention was to recruit twelve (n=12) participants, six YP (n=6) and six family/significant other (n=6). However, two (n=2 female) withdrew on the day I was scheduled to meet and interview them at very short notice. It was not the intention to interview each young participant at each specific stage of their cancer journey but rather understand individual experiences at different stages of the journey for the YP and their family/significant other. Table 3.4 illustrates the participant representation across Scotland, presented anonymously.

Table 3.4: NHS Scotland Health Board Participant Representation



NHS Scotland Health Board Participant Representation			
NHS Greater Glasgow & Clyde			2
NHS Grampian			4
NHS Lothian			4
Total			10
Participant Numbers	Male	Female	Total
Young People	4	1	5
Family Members	2	2	4
Significant Others	1	0	1
Total			10

3.6.4 Sampling

Convenience sampling was considered to provide the researcher with the most accessible participants, for example, all within the one geographical area, which would have been practical (Polit & Beck, 2010). However, this is not the most rigorous sampling types and would not gather the data required to answer the research aim and questions fully. Given the relatively small number of YP diagnosed with MM in Scotland each year, recruitment across the country was an important consideration. As a specialist nurse, I often cared for YP from the North of Scotland who had a different treatment experience through their cancer journey compared to those who lived in the densely populated 'central belt' of the country. I wanted to explore these different experiences from across Scotland rather within one specific region.

A purposive sample of participants identified by the CNSs ensured the sample was experiencing the phenomenon (Silverman, 2006). Also, it would have been a challenge to have recruited ten ($n=10$) YP with MM from one centre when there are only approximately 14 YP diagnosed per year with this disease across

Scotland (CRUK, 2019b; ISD, 2019). Purposive sampling allows the researcher to be selective in the choice of participants for the study and to ensure transparency (Bryman, 2008). Concerning purposive sampling, the size and the individuals selected are decided upon at the beginning of the study. In some forms of qualitative research, one should continue data collection until saturation has been reached, however in IPA it is not the quantity but the quality of the data that is important and the richness of the individual cases (Bryman, 2008; Smith et al., 2009). Typically, the number of interviews in IPA studies tends to be around 10-15 although as a PhD student Smith et al. (2009) suggest three to eight is sufficient given the volumes of data to analyse, categorise and interpret.

3.6.5 Access to Participants

Access to the Primary Treatment Centres (PTCs) in this study was granted via the research passport process with full compliance with the necessary Disclosure Scotland procedures, as shown in Appendix 1. Professional indemnity insurance for the research was arranged through ENU and the Royal College of Nursing (RCN).

3.6.6 Ethical Considerations

Ethical considerations are important within the context of healthcare research because any exploration which has an impact upon the lives of people can generate ethical problems (Beauchamp & Childress, 2001). Ethical considerations were an initial concern in the planning phase of this study, particularly around the restricted size of the potential sample population spread across the three centres and the possible concerns around maintaining participant anonymity. These ethical issues were considered throughout the development, implementation and execution of this study and in particular around the IPA methodology employed. The adoption of the IPA methodology presented several ethical challenges including avoiding any risk of harm when talking about sensitive and personal issues, and the need to ensure informed participant consent at every stage in the research process.

3.6.7 Ethical Approval

As a registered Child Health Nurse, the researcher is professionally accountable for ensuring that the ethical principles such as autonomy, non-maleficence and beneficence are integral to professional practice (Nursing and Midwifery Council, 2018) and was aware of this when considering the age of the participants that would be included within the study.

Ethically it would have meant gaining access to the children's hospital centres along with TYA units and adult centres. After careful consideration of the ethical issues, and the need to recruit participants within a realistic timeframe, the age range for participants was increased from 13 to 24 years of age to include those aged 16 to 26 years old for both practical and ethical reasons. This change was endorsed by the researcher's own Higher Education Institution (HEI), ENU and the NHS Integrated Research Application System. Increasing the age range meant that recruitment could be commenced quickly within the agreed research timescale, and there were fewer administrative requirements as the number of specialist centres reduced from six to three.

The first step in the ethical approval process was to obtain the consent of the ENU Ethics Committee. In tandem, the researcher applied to the NHS Integrated Research Application System to attend the next appropriate Standards and Ethics Committee (SEC) meeting. The researcher, along with the Director of Studies, attended the SEC meeting on 28th September 2016 in Edinburgh, to obtain the committee's approval and support for the proposed research. The 18-month ethical approval process is summarised in Figure 3.3.

Figure 3.3: Timeline



During December 2016, both in-house HEI ethics committees (FHLSS/1787 Version no.2) and NHS Lothian consented to the proposed research programme and approved access to the required research participants (2016/0319). This access to the individual participants was valid until 12th December 2017. Subsequent to NHS Lothian approving the research, a formal Research Passport was required to obtain multicentre approval from three NHS Boards across central Scotland. Formal approval for the Research Passport was obtained in January and February 2017 for each of the three sites, after several review meetings, including attending the Clinical Trials Executive Committee (CTEC) at the Beatson West of Scotland Cancer Centre in Glasgow. Data collection in each of the individual sites commenced shortly after formal approval was received. Copies of the relevant ethical approval communications are included in Appendix 2, 3, 4 and 5. It was clear that there would be challenges in gaining access to the patient group and this was recognised by both the SEC committee and the researcher. Within the agreed timeframe, the required numbers of participants were recruited to the study. I intended to recruit six YP (n=6) and six family/significant other (n=6), however ten (n=10) YP and family/significant other were recruited.

3.6.8 Recruitment of Participants

The key to the successful recruitment of the participants in this study was the supportive relationship and rapport established with the CNSs at each individual site. The CNSs were aware of the inclusion/exclusion criteria before the

recruitment of the participants, and they were responsible for ensuring the criterion was followed. Without them, recruitment would not have been so swift. This part of the study was undertaken from January to November 2017. Due to the relatively small numbers of YP diagnosed with MM in Scotland, five (n=5) YP and five (n=5) family/significant other were recruited to the study. There were four individuals (n=4) and three dyads (n=6).

Participants were recruited from three NHS Boards across Scotland. These were the three PTCs for Adults and did not include CYPs services. Recruitment was from the adult PTC's depending on where the young person was receiving care at the time of the research. Young people and their families/significant other from remote and rural areas were identified through the PTCs to ensure that YP with this disease from remote areas were included within the research. Young people were given the choice of an individual interview, or with the person, they chose as being paramount within their cancer journey. As discussed previously in Chapter 1, recruitment was facilitated and supported by the Scottish Skin Cancer Nurse Specialist Group (SSCNG), who acted as gatekeepers to the research population. The SSCNG invited the researcher to discuss the proposed research before the study commencing.

Table 3.5 summarises the main characteristics of the research population included in the study. All names are pseudonyms to protect individual privacy and confidentiality. There were a larger number of males to females, and most of the YP choose their mother or father to be included within the study as opposed to significant other as friend or partner. Helen chose her partner as her family lived in southern Europe.

Table 3.5: Research Sample Population Characteristics

Participant	Age at Diagnosis (Years)	Age at Interview (Years)	Stage of Disease	Occupation at Interview	Family / Significant Other	Age at Interview (Years)
John Male	16	19	2B	University Student	Eve Mother	52 ¹
Paul Male	21	23	3A	Health Administrator	Anna Mother	52 ¹
George Male	21	23	3A	Mechanic	Richard Father	72 ²
Patrick Male	11	16	3B	Starting College	Terry Father	38 ²
Helen Female	25	26	3B	Hotel Manager	Stuart Partner	26 ²

(1= single interview). (2 = dyad).

Table 3.6 summarises the biographical narrative of each the anonymized individual participants.

Table 3.6: Research Population Biographical Narrative.

Participant	Research Population Biographical Narrative.
John Dyad: No	John, a young male, was 16 years of age when he was diagnosed with Stage 2 MM on his neck. The mole and part of the lymph were surgically removed, and no further treatment given aside from routine follow-up check-ups. The surgery has left a scar. They are a close family with support from extended family and friends.
Eve Dyad: No	Eve, John's mother, was 52 years of age and a registered adult nurse. Both mother and son had a close bond. Since the time of diagnosis Eve had been blaming herself for the disease. John's father suffers from anxiety and depression, which prevents him from working.
Paul Dyad: No	Paul, a young male, was 21 when he was first diagnosed with Stage 1 MM. The mole was surgically removed, but the MM reoccurred six months as a Stage 3 MM. Further surgery was required and followed with regular check-ups. Paul has widespread scarring on his neck as a result of the surgery. Growing up, he suffered from bad acne and was on medication which contributed to his severe depression.

Anna Dyad: No	Paul's mother, Anna, is 52 years of age and worked in insurance. Anna was separated from Paul's father and had one son, Paul. Although mother and father were separated, they remained a close family.
George Dyad: Yes	George was first diagnosed with Stage 3 MM at the age of 21. The surgery left a scar to his head. Regular follow-ups continued. George lived at home with his parent's, twin sister and two other older sisters. The family lived in the country far from the specialist hospital but had easy access to private transport.
Richard Dyad: Yes	George's father, Richard, is in his 70's had cared for George and his twin since birth. They were a close family unit and lived in the country.
Patrick Dyad: Yes	Patrick was a young child of 11 when first diagnosed with Stage 3 MM in his leg. He was first diagnosed in 2011 then again in 2015. He lived at home with his father and younger brother. He had missed a lot of school from being in hospital.
Terry Dyad: Yes	Patrick's father, Terry, cared for his two sons. Patrick's mother did not live with them. Terry lived some distance from the hospital but was able to drive.
Helen Dyad: Yes	Helen, a young woman, lived with her partner, Stuart. At the age of 25, she was diagnosed with Stage 3 MM on her abdomen. The mole was removed, followed by surgery to remove those lymph nodes that were affected. The surgery resulted in extensive scarring to Helen's arms and abdomen, and she was waiting to receive immunotherapy at a Specialist Centre.
Stuart Dyad: Yes	Stuart and Helen had been together for two years and lived together. He had been a great support since the initial diagnosis. Stuart had family close to where they lived.

3.6.9 Informed Consent

The principle of informed consent is enshrined in research practice, and mandates that prospective research participants should be given as much information as they require in order to make a voluntary informed decision about whether or not they wish to participate in the study (Bryman, 2008). As the CNSs were the clinicians who had access to the patients, they were able to identify those patients suitable for inclusion within the research. This allowed the YP not to feel coerced into being part of the study and could say no freely to their CNS, the person whom

they trusted. It was essential that informed consent was given and that they felt safe and confident during their participation. The researcher had to trust and rely on the CNSs who were the gatekeepers to support the recruitment phase of the study, which they enthusiastically supported. Within this process, gatekeepers had a key role in ensuring that researchers gain access to potential participants and sites for their research. Positive influences from the gatekeepers can be invaluable to the research process by facilitating the smooth running of research activity to completion (Miller, Birch, Mauthner & Jessop, 2012) and is favoured by the ethics committees. However, gatekeeping is not always a positive experience and can be challenging for some researchers, an example being where the gatekeeper may not want the patient to be involved in the research as a way of protecting them (Polit & Beck, 2010).

The CNSs reviewed the Participant Information Sheet (PIS) and provided feedback before the PIS was discussed with potential participants. This was to ensure that the language within the PIS would be understandable for the participants to read. The CNSs were responsible for ensuring they understood the study before obtaining informed consent. The young person then chose a family member/significant other who was experiencing the cancer journey with them. This was explained to them by the CNS when the PIS was issued. The PIS was then given to the family/significant other by the young person before the researcher gaining consent from them. The PIS stresses the voluntary, anonymous and confidential nature of the research and Appendix 6 and 7 shows the PIS utilised for the YP and the family/significant other.

Under Scottish Law, young people between 16 and over can make decisions about their own treatment and care and were able to give informed consent to their participation in the research (Scottish Government, 2014). Although the young person was able to provide informed consent, it is seen as good practice to involve the family where/when necessary. Appendix 8 shows the Informed Consent documentation for the YP and Appendix 9 contains the family/significant other document. It was not always possible for both to be given out together as the young person often attended the outpatient clinic appointment without their family/significant other.

3.6.10 Risk to Participants

A diagnosis of cancer for the YP and their family can be devastating in many ways (Grinyer, 2007). The YP and family require a great deal of support, especially if the disease is incurable, and the researcher must be sensitive to this. The researcher has worked for over 30 years within this area of care, although mainly with children (Paediatric Oncology Nurse) and was very mindful of how upsetting it can be for the patient and their family. I was also mindful of being the independent researcher and not the professional nurse caring for the YP and their family.

Due to the nature and timing of the study, YP may have unwell at the time of the interview, especially if undergoing treatment or were receiving palliative care. Participants may also be anxious or distressed when being interviewed. If this occurred before and/or during the interview, then it would be abandoned. If the young person or family member did become upset, the CNS would be notified and advice sought after the interview. It was agreed with the CNSs at the outset that information regarding the patient and family would be discussed before the interview and after gaining consent. It was also discussed with the participants, that if I was unduly worried that the interview had uncovered any challenges, I would inform their CNS. These risks were therefore managed by ensuring the participants were fully briefed and debriefed before and after their interview and advised if any distress arose. I was also mindful not to disclose any information that I had gathered from the YP that the family member was not privy to and therefore had to ensure confidentiality throughout. Appendix 10 shows the Risk Pro-Forma for the participants.

For the reasons discussed above, the YP themselves decided when and where the interview should take place within the hospital and if they chose to be included in the study or not. This was discussed in detail with the YP and the CNS before I was contacted. They were assured that withdrawal at any point would not affect their care delivery in any way and that the researcher fully understood if this should happen. No one was coerced into participating in this study, and this was agreed with the CNS from when recruitment began. As a CNS for many years and as the

researcher of this study, I was fully aware that YP and others should be given this option in a non-threatening and non-judgemental way. As discussed previously in this Chapter, two young female participants withdrew from the study, on the day I went to interview them. Both participants came from the same geographical area, and a train journey of three hours was required to reach the destination. I had also contacted the specialist centre to ensure a quiet room for the interview was available. Both withdrew, on different days, and for varying reasons. An alternative date was offered, but I did not pursue this as it became clear they did not want to continue their participation in the research. Participants were debriefed appropriately and provided with a Participant Debriefing Letter by the researcher and/or CNS (Debriefing Letter) after the interview, as shown in Appendix 11.

3.6.11 Confidentiality and Data Handling

The Nursing and Midwifery Council, (NMC) (2018) states that nurses are professionally accountable for ensuring that confidential patient information is fully protected at all times. In this context, confidentiality has two fundamental elements. Firstly, the storage and handling of all data which contains personally identifiable details is a significant responsibility for the researcher and must be subject to robust and secure handling procedures. Secondly, the assurance of anonymity is based on these underlying procedures and intricately linked to maintaining the confidential nature of all patient information.

In order to maintain participant anonymity, all publications and reports supporting this study, including this document, do not contain any identifiable individual information. All participants were allocated pseudonyms to protect their anonymity (Gerrish & Lacy, 2010) but it may be possible that some individual participants could be able to identify themselves through the inclusion of specific interview quotes and excerpts. However, individual confidentiality is assured as these alone should not be identifiable to others.

To protect anonymity, the recordings and interview transcripts, audio files and field notes were stored in a secure computer and cabinet in ENU, which only the researcher could access. These materials are scheduled for destruction after

completion of the study and participants will be informed of this in writing. Destroying of all the research materials associated with this thesis complies with the General Data Protection Regulations 2018, a regulation in EU law on data protection and privacy for all individuals within the European Union and the European Economic Area.

The data from the interviews are presented in an anonymised format which is in keeping with ethical guidelines for qualitative research. A random participant name was used to anonymise the participants in the data files and to bring the participants stories to life. This approach was in keeping with the idiographic underpinnings of IPA and the use of codes depersonalised the data.

3.7 Data Collection

When considering how to engage YP and their family/significant other, multi-modal methods were considered and discussed with my supervisory team (Glasscoe & Smith, 2011). Multi-modal methods involve the gathering of data from different perspectives, such as through an interview and use of visuals. In the beginning, I was keen to use a multi-modal method to collect data which would include using images and emotional touchpoints to encourage the participants to talk (Dewar, MacKay, Smith, Pullin & Tocher, 2010). As the study would involve YP, I was concerned that they would not wish to communicate their story with me. However, I decided against using emotional touchpoints as they risked distracting the focus away from the questions I was seeking to answer. I also discussed carrying out the data collection at the well-known annual conference in the UK – Find Your Sense of Tumour.

Focus groups over the last ten years have gained acceptance within nursing research and are popular in qualitative studies as they are designed to obtain in-depth information in a non-threatening way (Polit & Beck, 2010; Parahoo, 2014). However, due to the nature of the IPA and that the participants are from different parts of Scotland, this would have been problematic and costly to have a group at one particular place and time and therefore was disregarded. In addition, through observational techniques, the researcher observes and records behaviour, but

does not interact with the participants. This method provides data collected within the natural setting of the participants but is often complex and time-consuming. Although all the above were considered, after discussion with supervisors, these were disregarded, as they would not yield the data required concerning the IPA approach.

From the IPA perspective, understanding becomes possible through language, and therefore dialogue is essential. After much deliberation and considering the nature of the questions, I decided that the individual semi-structured interview would meet the requirements of this thesis and answer the research questions (Parahoo, 2014; Smith et al., 2009). However, as the YP were offered a choice about being interviewed individually or as a dyad, with their family/significant other, recent literature suggests that within IPA this is concerned with exploring a shared and distinctive experience which is important to two people. Larkin et al. (2019 p186,) refer to this as a multi-perspective design, or “two sides to every coin”.

3.7.1 Semi-structured Interview

As discussed in the above section, in-depth semi-structured interviews were conducted with the participants from across Scotland. I intended to interview the young person first, but due to practical reasons and the need for some of the YP to be interviewed with their family/significant other, some were interviewed as a dyad. The first four (n=4) were individual interviews with six (n=6) being completed as a dyad. YP and their fathers and YP and their significant other.

A social phenomenological perspective demands an emphasis on understanding the participant's experience of the world from their situation, and then interpreting how that understanding is inter-subjectively constructed (Eatough & Shaw, 2019; Eatough & Smith, 2008; Willig, 2011). In-depth interviews, therefore, offered an appropriate and compelling method to generate data which permitted such insights and reflections, allowing participants to reconstruct their understandings of a phenomenon (Smith et al., 2009) verbally. Conducting interviews face-to-face as opposed to over the telephone or via email also allowed the establishment of rapport, an important consideration when discussing sensitive topics such as

cancer and life experiences. The semi-structured interview enabled all participants to be asked the same core questions. Unlike the structured interviews, this design also allows for flexibility in the phrasing and the order of the questions being asked (Parahoo, 2006). This was an important feature as the participants all had various experiences, such as the ages and family dynamics of the individual YP.

When planning the study, the Ethics Committee recommended that participants should not be interviewed at 'home' or in a 'cafe' but be approached when attending a suitable outpatient clinic appointment. This would minimise any disruption to the participants' daily schedule and was included within the final research methodology. Interviews took place within the hospital environment in a private, quiet and comfortable area on the day of appointment or hospital visit to avoid any further personal disruption. All travel and subsistence costs were paid by the researcher if required. Using a familiar environment, specific to situated experiences of phenomena is suggested to enhance recall and solicit rich descriptions (Bloomberg & Volpe, 2008). The interviews lasted between 60 to 145 minutes depending on if they were a dyad or individual and the length of the contributions made by the participants. It is suggested that participants may become tired and lose concentration after this time (Kvale, 2007). This can be said for the researcher also. A research interview does not merely 'collect' data, but instead generates accounts of lived experience and its meaning through an exchange of views and dialogue between the participant and the researcher (Kvale, 2007). The data is collaboratively produced within the relational context of the interview, with the researcher helping the participants to reach beyond the superficial layers of their experience in order to generate rich, novel and informative insights (DiCicco-Bloom & Crabtree, 2006). This was achieved through my own professional knowledge and experience as a nurse and academic. The interview schedule for the YP is presented within Appendix 12 and for the family/ significant other in Appendix 13. This provides a flavour for the types of questions that were asked of the YP and the family/significant other.

The researcher was also able to probe the respondents where clarification was necessary (Bryman, 2008) by asking subtle questions so they could follow through with their experience. Although the telephone interview was a consideration due

to the geographical distance between the researcher and the participants, the telephone interview is less personal and generates different data. It would have been impossible to gauge the participant's body language and other non-verbal communication in order to accurately describe their feelings and experiences, without actually talking to them while observing them at the same time (Bryman, 2008). The main limitation of the semi-structured interview was the time constraint, as the participants were from across Scotland and all were interviewed after/before their clinic appointment. The researcher required to be strict as there may be a tendency to exceed the time allocated for each interview. The researcher gave careful consideration when switching off the digital recorder, as vital data is often lost if the recorder is deactivated too soon (Bryman, 2008). As part of the interview planning process, interruptions were prepared for and in most cases did not occur. The semi-structured interview was an appropriate method of data collection as participants were very keen to talk, except one young participant who found it difficult to enter into the conversation and often left this to his parent. Perhaps the use of an audio-diary (Polit & Beck, 2010) for this young person would have been more appropriate, and they could have completed this at home and then returned it to me.

Qualitative studies require consistency in the way in which data is collected so that there is fairness for each participant. An awareness of personal characteristics and how the questions were asked was identified, as there may have been a tendency for the participants to respond in a fashion that would please the researcher (Fossey, Harvey, McDermott & Davidson, 2002). The researcher, therefore, strived to facilitate a naturalistic and responsive interview as described by Bryman (2008). This includes the use of conversational language, incorporating terms used by the participants with attention to non-verbal communication, to convey an open, respectful and non-judgemental attitude. As paediatric oncology is the researcher's specialist area, supervision was vital throughout the whole process to reduce subjectivity and guard against the possibility of coercion and bias (Polit & Beck, 2010).

The researcher was also aware of what Roethlisberger & Dickson (1939) highlight as the 'Hawthorne Effect', where the observer's presence (researcher) cannot be

fully eliminated, which may lead the participants to behave in ways that are not 'normal' for them (as cited in Parahoo, 2006). In considering this theory, although not observing the participant's behaviour, the researcher was aware of the participants' non-verbal communication in the answering of the questions. The nature of the questions was sensitive, and the participants were assured that the content of the interview would be treated with the strictest confidence with all personal identities disguised by pseudonyms to ensure the anonymity of individuals and their place of employment (RCN, 2004; Orb, Eisenhauer & Wynaden, 2001). The participant's confidentiality was highlighted verbally and in writing and hopefully enabled the participants to share information in a non-threatening way.

In carrying out the interview, it was clear that I had to ask the participants what was important to them. The first interview was the 'pilot' or trial run, which allows the researcher time to gain confidence in their study and prepare them for the remainder of the interviews (Polit & Beck, 2010). This was important in moving through the data collection as I strived to be the 'researcher' and not the 'nurse'.

3.7.2 Recordings

All interviews were digitally recorded with the participant's permission and transcribed verbatim. The recording is regarded as being best practice and ensures the rigour of the data collection process, but it is recognised that it may also be intimidating for people to have their conversations recorded (Silverman, 2006). Before the interview and as part of the PIS, this was explained so that participants were fully prepared. The device I used was small, so did not seem to intimidate any of the participants. In practice, all the participants consented to the recording of the interviews prior to the interview commencing.

The interviews were recorded digitally and then uploaded onto the researcher's computer and then shared with an external transcription service via a secure website to be transcribed. No notes were taken during the interviews as there was a requirement for the researcher to be fully immersed in the topics being discussed and to give the individual participants full attention. I felt to take notes would have been intrusive to the interview process. I did, however, make extensive field notes

following each interview, noting aspects such as how I was welcomed, what the dynamics felt like and key issues that were immediately apparent. Sometimes this was done on the digital recorder and others I wrote directly into the research diary. After the first four individual interviews, the CNS within one of the PTCs was present to speak to after. This was a great help in processing what had been discussed. I was also able to relay any worries I may have had about the participants, which had been agreed as part of my ethics approval. This was to prevent any risk occurring to the YP or their family/significant other. This approach was not repeated in all the other PTCs as the CNS was unavailable. During the data collection, the recorder was always kept in a securely locked drawer when not in use.

3.8 Data Analysis

Using a systematic approach, and with the respondents' consent, interview data were analysed using an inductive interpretative approach (Smith et al., 2009). Transcription of the data can be arduous, but as the literature suggests it is advisable to transcribe some if not all, in order to capture the actual essence of the material (Bloomberg & Volpe, 2008). Nevertheless, some researchers prefer to use other methods to immerse themselves in the data and have secretarial companies complete the transcription, however, this can be costly. For this study, the researcher opted to transcribe a small number personally and sent the remainder to a professional secretarial company. Once data transcription was complete, the researcher had the choice of manual data analysis and/or support from a computer-assisted qualitative data software called QSR NVivo. Each transcript was analysed separately both for the YP and then the family /significant other, whether as an individual or dyad. This was important as I was not sure at this stage whether the findings for the YP would be different from that of the family/significant other at this stage of the process.

3.8.1 Processing of the Data

QSR NVivo was used to facilitate the analytic process with the option of moving to a traditional 'pen-and-paper' approach with specific attention paid to the

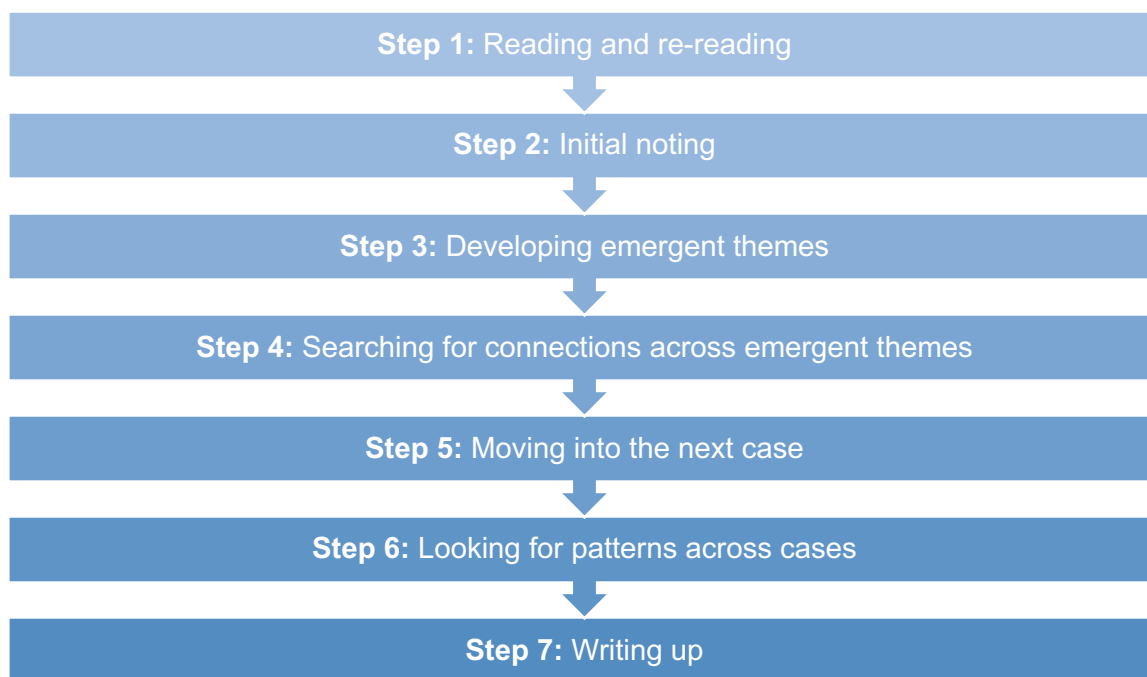
transparency and consistency to ensure its dependability (Bryman, 2008). The QSR NVivo software was of great assistance initially in classifying, sorting, filing and retrieving data (Bloomberg & Volpe, 2008). Although the software is designed to support and assist in the management of the data analysis, as Bloomberg & Volpe (2008) suggest, it does not suit all researchers. In utilising this tool, I found that ultimately the software did not fully 'open up' and reveal the experiences of the participant's as various 'individual parts' and then as a 'whole' population as I did not feel fully immersed in the data through this tool. As a result, and in keeping with IPA, I moved to a more traditional manual analysis methodology, utilising the tools available through the Microsoft Office 365 suite. Appendix 14 illustrates how each sentence and section of the transcription was subsequently examined to expose meaning and identify the experiences of each participant in keeping with IPA.

The Microsoft tools meant that I could listen to the transcript and code at the same time. Data analysis is a continuous, reflexive process, with initial data analysis guiding subsequent data collection until no new findings are identified and is vital to the success of any research study (Rolfe, 2006). Utilising the software tools, individual interviews were analysed and coded, and then emerging sub-themes were systematically refined into a smaller number of super-ordinate themes (Bryman, 2008). Each sentence and section of the transcription was subsequently examined to expose meaning and identify the experiences of each participant.

As discussed earlier in this Chapter, a branch of phenomenology was used to interpret the data. Through IPA, I had to strive to find meaning from the participant's experiences and to interpret this through an understanding of what they were telling me. Larkin & Thompson (2012) discuss the level of flexibility within IPA, describing the "considerable room for manoeuvre" within analytical strategies, which are influenced by the research itself and the interaction between the researcher and the participant. Nonetheless, Smith et al. (2009) provide guidance within the analytical process which ensures a systematic approach to help the researcher focus on the level of interpretative analysis that is required within IPA. The seven-step approach by Smith et al. (2009) was adopted, as seen in Figure 3.4. Further insight and guidance was provided through an IPA

workshop, 'Thinking Qualitatively', delivered by Dr Chris Darbyshire (2019) during May 2019. This section provides an overview of the structure and in relation to the theory for the first six steps. The thesis as a whole is presented as step seven in the process.

Figure 3.4: Key Steps



Adapted from: Smith et al. (2009)

3.8.2 Seven-Step Approach

Step 1 in the IPA analysis is reading and re-reading the data transcripts. This step is congruent with immersing oneself in the data and to ensure that the participants' account is the focus of the analysis. As already explained, the researcher transcribed some of the interviews personally, and the remaining were sent for external transcribing. However, re-listening to the interviews can also help familiarize the researcher with the flow of the interviews. Hale, Treharne & Kitas (2007) identified reading and re-listening to interviews as being helpful in 'recapturing emotion and intonation'. It was useful to repeat this step as there had been some considerable time lapse between collecting the data and analysing it, apart from some initial rudimentary analysis undertaken through field notes and my reflective diary. Whilst it could be argued that the time-lapse was not ideal, as

many qualitative researchers suggest data analysis should occur concurrently with data collection, this was borne out of necessity and in fact, proved to be useful as I found returning to the data provided me with a fresh approach, which allowed a more analytical stance.

Step 2 involved initial noting, which was challenging but also creative as there are no rules to what to comment on (Smith et al., 2009). Following the IPA framework, I was able to explore and comment on including the descriptive keywords and phrases, linguistic and conceptual comments. This step of the initial level of analysis was the most detailed and time-consuming. As I moved through the analysis process, I became more familiar with the process and the data. I found that Steps 1 and 2 often merged. During this stage of the analysis, I also had the opportunity to attend an IPA programme/series of workshops facilitated by Professors Paul Flowers and Michael Larkin; two of IPA's founding authors. This opportunity provided me with a valuable learning opportunity which gave me confidence in my own analytic ability, as well as the procedural elements of doing IPA. While at the IPA workshops, the class were able to discuss and share notes. In this step, initial noting includes making different types of comments on each transcript including descriptive comments which help explain interpretative processes and provide a body of comments from which to draw upon when making the interpretative account of the experience. This approach was instrumental in aiding the interrogative process of analysing the data. Smith et al. (2009) also suggest examining the narratives from a linguistic perspective to analyse the meaning of the situation for the participant further. An example of Step 1 and 2 can be seen in Appendix 15. In order to understand these codes more fully and identify any similarities between each of the participant responses, it was helpful to analyse the responses using a series of colour categorisations.

The development of the themes is Step 3 and is also part of the conceptual process, where the descriptive notes can be used as source data for this process. After initial coding, the next stage is to identify emergent themes. In this stage of analysis, there is a shift from engaging with a focus on the transcript to engaging with the initial notes, which Smith et al. (2009) propose, if completed comprehensively should be closely related to the original transcript itself. This shift

to coding should maintain complexity and depth, which was created through exploratory coding while also reducing the amount of data. Smith & Osborn (2007) identified that when identifying emerging themes, the researcher should use concise phrases to capture the essence of what was found within the narrative. Emergent themes should be both grounded in participant's accounts while moving to a high level of abstraction, whereby psychological terminology may become more apparent, for example 'life was put on hold', 'frightened and afraid'. This is where subthemes emerge, and the researcher then requires to sort these into themes to illuminate the experiences of the narrative as told to them. This part of the process can be described as almost like a tree with lots of branches, but the branches need to be attached to a stronger branch. Smith et al. (2009) stress the importance of the interplay between the participants and the researcher here, suggesting the researcher is actively engaged with the lived experience of the participant so that the resultant interpretation is based on the perspective of both. Themes become statements which explain the connection between the participant's transcript and the researcher's interpretation which captures an understanding of the experience. Appendix 16 contains an example of Step 3.

After identifying all emergent themes, Step 4 is to search for connections across emergent theme titles and all corresponding extracts. This step is particularly helpful in practical terms as a data management tool. In essence, Step 4 involved mapping emergent themes across the data set looking for similarities, connections and relationships within the data sets. This can be seen in Appendix 17. To assist in the analysis process, I produced a mind-map to illustrate the main themes of interpretation that appeared to be emerging from the data. This mind-map, shown in Appendix 18, was used to discuss these main themes with my supervisory team.

Smith et al. (2009) propose that remembering the importance of both the Interpretative and Phenomenology in IPA is essential for a comprehensive analysis, and emergent themes should move beyond mere description and instead mirror both the participant's words and the researcher's interpretation. The aim of identifying emergent themes is to engage with a more in-depth level of abstraction, which is reliant on the researcher taking a central role in the analysis.

Reflective journals, field notes in addition to transcript analysis, helped create deeper understanding related to the data.

The process described above is repeated for each transcript. As IPA maintains an idiographic ontological perspective, Smith et al. (2009) suggest that the researcher must epoché or 'bracket' their assumptions in an attempt to reduce any researcher bias that could influence the data collection and data analysis processes. As discussed earlier in the methodology interpretation is very much via the researcher's unique lens, informed by knowledge, experience, alongside reflexivity. Gadamerian hermeneutics approach rejects the notion of bracketing, instead embracing the active engagement of the researcher and their developing understanding as part of the process. I also believe that to truly bracket one's experiences is not possible within IPA and engaging with the participants and their life stories (Peat et al., 2019; Wilson, 2018). Therefore, I consistently followed the double hermeneutic circle, framework and steps by Smith et al. (2009). To ensure all the voices and narrative were heard, I required a visual in order to ensure all participants were represented and the experiences shared. The thematic mind map, as seen in Appendix 18 this and my ability to articulate to some of my colleagues to support me in finding reassurance in my findings. This was when the realisation of the sequential journey arrived and therefore, has been showcased in this way.

Step 5 involved moving into the next case. After completing steps 1 to 4 of the analytical process, Step 5 involved repeating the same process for each participant/dyad to bracket assumptions and ideas which have been revealed earlier. Following guidance from Smith et al. (2009) the goal is to treat every transcript with fresh eyes with the aim to bracket assumptions and ideas which have become illuminated through previous analysis. Although this is not always entirely possible, following a systematically analytical procedure can help to minimise any priming which has been created through previous data analysis to ensure that new themes emerge. As expected, similarities between participants emerged as the analytic process continues, and emergent themes began to repeat through the transcripts.

Following the completion of the individual-level analysis, the next stage of the analytical process was Step 6. Once key themes were identified, Step 6 was to look for patterns across each case and involved abstraction and moving away from the idiographic underpinning of IPA. This meant searching for meaning in each of the cases presented and developing a new identity for the theme that encapsulated the shared experience. This was resolved by identifying the shared experience common across the themes and extracting the super-ordinate and sub-themes for each participant (Larkin & Thompson, 2012). At this stage, the researcher is seeking patterns and connections across the cases, recurrent themes, and exploring the possibility of themes in one case being able to solidify or illuminate themes in another. At this stage, I reorganised, edited and modified the themes, highlighting the iterative analysis processes within IPA. In this process of moving to group-level analysis, the researcher can engage with ideas of the hermeneutic circle looking for similarities to deepen the level of interpretation. Emergent themes naturally cluster together and from this main themes/superordinate themes and subthemes arose from across the whole data set.

As the participants were young people with MM and their family/significant other, the IPA method allowed me to examine the data for similarities and differences in how MM is experienced from each of the participant's perspectives. Since I had given the participants the choice of being interviewed individually or together, the different combinations of data sources presented challenges for the analysis process but also had advantages as the multiple perspectives of the experience were exposed. The difference in interviews was also interesting as the dyads who were interviewed together prompted each other at times during the interview, arguably revealing more and different information than they would have if interviewed separately. However, those who chose to be interviewed apart also reported telling me more than they would have about the effect of living with MM either from the young person's perspective or the parent/partner. The writing-up of the findings is discussed in Chapter 4 following a process of iterative and reflexive consideration.

3.8.3 Quality Assurance

There are many frameworks available for assessing the quality and robustness of qualitative research (Elliott, Fischer & Rennie, 1999; Yardley, 2000). Rolfe (2006) suggests that there should be no rigid generic framework to establish rigour, as this has the potential to thwart the authenticity and creativity of the individual study. While IPA is firmly established as a rigorous qualitative approach (Eatough & Shaw, 2019; Wilson, 2018), some continue to try and challenge the scientific quality of IPA (Smith, 2010; Paley, 2014).

The concerns relating to the level of freedom and creativity researchers appear to have regarding how IPA is performed, make it challenging to ensure the findings are credible and trustworthy (Smith, 2010). From the phenomenological perspective, IPA is more aligned to the philosophy of Heidegger than Husserl, with a strong focus on interpretation (Finlay & Ballinger, 2006). Furthermore, Smith et al. (2009) vigorously defend IPA, arguing that while qualitative methodologies are prescribed distinctly from quantitative methodologies, the strength of IPA lies in the intellectual and intuitive work performed at each stage (Smith, 2010).

Interpretative Phenomenological Analysis is based on guidelines for good practice rather than strict adherence to specific frameworks, thus high-quality IPA research relies on the researcher's professional and personal abilities and their proficiency in managing the complex demands at each stage of the process (Smith, 2010) for which training and education are essential (Smith et al. 2009). Yardley (2000) presents four broad principles for assessing the quality of qualitative research and in particular within IPA; (1) sensitivity to context; (2) commitment and rigour; (3) transparency and coherence (4) impact and importance (Smith et al., 2009).

Yardley's (2000) first principle is sensitivity to context, which begins in the early stages of the research process, and this was evident when considering the patient group and the ethical approval requirements. As my study concerned YP and their family/significant other living with MM, sensitivity was requested within the ethical approval process, mainly around the topic and where the interviews would take place. Yardley's second broad principle is commitment and rigour, which was

demonstrated in a number of ways and can be synonymous with the first broad principle. Commitment to the study was shown through my dedication and passion for this research and my commitment from the beginning of the PhD journey to the end. Throughout, I have strived to be reflexive and be aware of any personal bias resulting from the experiences I discussed earlier in the Chapter. According to the literature, reflexivity enhances the rigour and credibility of the IPA study, and this was also achieved through the multiperspective design I adopted (Larkin et al., 2019). During the process, triangulation of data collection and analysis was utilised as a quality indicator to ensure credibility and achieve a rounded multiperspective understanding of the research topic (Elliott et al., 1999). The use of triangulation also built upon the rigour of searching and identifying the shared experiences, common in IPA. Convincing transparency and coherence in the presentation of the analysis and empirical data, Yardley's third principle, was achieved by detailing every aspect of the data collection process and the framework used to code the data. Throughout the data analysis section, I presented the six steps of the data analysis to support the rigour, transparency and coherence of the findings. In addition, transparency refers to the degree to which all relevant aspects of the research process are disclosed, and my research has followed this throughout.

The IPA approach is inherently idiographic and does not seek to find one single truth (Wilson, 2018; Yardley, 2000). Yet, it recognises the possibility of drawing single cases together for further analysis and moves towards more general claims based on exploring the particular more closely, and in essence the individual experience becoming part of the whole (Smith, 2019; Eatough & Shaw, 2019). Rather than empirical generalisability, it is more appropriate to consider IPA in terms of impact and importance, Yardley's principle four, (Yardley, 2000; Smith et al., 2009) or as theoretical transferability which is consistent with other qualitative paradigms. Widespread dissemination through the CNS network, broader nursing education and practice along with further detailed exploration, will extend the impact, reach and importance of my research findings.

The principles outlined above supported and maintained an interrogative and interpretative stance when reviewing and analysing the research narratives (Smith

et al., 2009). I aligned myself within the social constructivist/interpretive approach that is aligned to the work of Heidegger and Gadamer as this in close alignment with my personal and professional interests, the IPA approach and my experiences as an academic, researcher and a nurse.

3.9 Summary

This Chapter has provided a comprehensive overview of the methodology that underpins my selection of an IPA approach to answer the stated research aim and questions. It has illustrated how the theoretical perspective of IPA has guided the applied research practice, alongside the practical methods for this study. Engaging in this methodology of qualitative enquiry allowed constructive and insightful interpretative accounts of experiences that enrich understanding and reveal prominent matters within healthcare. Interpretative Phenomenological Analysis (IPA), offers a rigorous, somewhat structured, yet open and flexible way to perform research into specific lived experience (Larkin & Thompson, 2012). The robust theoretical foundation of IPA locates the research directly to participant's experiences, while meeting the framework described by Flowers, Smith & Larkin (2009). Larkin & Thompson (2012) clearly outline the theory and processes of IPA, which, when new to this qualitative approach, was helpful, building upon my own interest in philosophical theories and approaches within healthcare. Growing support exists for the use and recognition of IPA as a rigorous qualitative methodology, which yields value in healthcare research (Smith et al., 2009). IPA allows more room for creativity and freedom than other approaches (Willig, 2011) and provides an element of 'giving voice' (capturing and reflecting upon the principal claims and concerns of the research participants) and 'making sense' (offering an interpretation of this material, which is grounded in the narrative accounts of the individual participants (Eatough & Shaw, 2019).

The following Chapter 4 presents the findings, meticulously drawing upon the three philosophical perspectives; phenomenology (examining the lived experience), hermeneutics (interpretation of the lived experience and idiography (attention to particulars of individual stories). The researcher has attempted to

elucidate the participant's experiences of the phenomenon through the final emerging four super-ordinate themes, and 12 sub-themes.

Chapter 4: Research Findings

4.1 Introduction

This Chapter aims to provide a rich insight into the experiences of YP living with MM and that of their family/significant other. Smith et al. (2009) suggest that as a novice IPA researcher, the discussion Chapter should be written separately from the findings. This allowed the researcher to be fully immersed in the interpretation of the narratives and findings without reference to the literature. Throughout the iterative analysis process, I strived to explore the essence of what the participants felt was real, true and important *to them* at this time. This reflected the epistemological and ontological foundation of IPA, which was fully discussed in Chapter 3 (Smith et al., 2009). In understanding that experience is subjective, and that IPA is concerned with the meaning of what people experience as a phenomenon rather than a direct reality, this was achieved through continuous adherence to the hermeneutic and idiographic nature of the IPA approach. Working within the hermeneutic circle, constantly and dynamically moving between the individual experiences along with the data set as a whole, I have carefully selected individual comments and stories from specific participants to illuminate each of the super-ordinate and sub-themes while being mindful of the idiographic nature of the study. This section of the thesis presents the findings from the multi-perspective design, through the individual or dyad interviews (Larkin et al., 2019). This was necessary as I worked through each of the interviews aiming to bring meaning to this thesis and its findings.

In order to present a consistent analysis of the participants' lived experience, a multi-perspective design supported by regular supervision supported my interpretation of the dataset was rigorous, credible and trustworthy (Larkin et al., 2019). This approach was consistent with the IPA framework suggested by Smith et al. (2009). The detailed analysis of the lived experiences identified four super-ordinate themes and 12 sub-themes, which encapsulate the experience of YP living with MM and that of the family/significant other. These super-ordinate themes are presented in Table 4.1.

Table 4.1: Super-ordinate and Sub-themes

Super-ordinate	Sub-theme	Sub-theme Summary	Theme Summary
Is it Serious?	Suspicious findings...what is it?	Wondering about the change to their mole	Finding and seeking support for the change in their moles, then worrying about the result and diagnosis
	The waiting game	Waiting to be taken seriously and worrying about the mole	
	Being diagnosed	How this diagnosis is reached and communicated	
Too Much too Young	In-between	Being young and having cancer	Being young and being diagnosed with MM and what this means
	Uncertainty and fear about the future	Life on hold and fear of the unknown	
	A sense of guilt and helplessness	Feeling guilty and not fully understanding why this had happened to them	
Not the Same	A life less ordinary	Trying to adjust and cope with their new life circumstances	Living with MM and the treatment experience which is different from other cancers
	The treatment experience	Where, when, how and from whom they received care	
	Feeling a fraud	Not like other patients with cancer	
Time to Live	The scars tell a story	The physical and emotional scars tell their story of MM	Realising not on the same path as they were but with new meanings to their lives
	Supportive relationships	Supportive family and friends being important within the journey	
	New meanings	Being positive, even when worry prevails	

At the outset, I recognised that the experiences of many YP and their family/significant other could not be neatly separated and therefore decided to offer the YP the option of being interviewed separately or together. This was a practical solution as both the young person and their family/significant other often attended the clinic appointments together. This was an interesting finding in itself, as it was clear from the data that YP and their family/significant other were experiencing the MM journey jointly, and their experiences were interconnected. Due to these close interconnections, I opted to present the findings together and are not categorised by YP or the family/significant other. Young people in the 16 to 26 age group may often find themselves experiencing a 'boundary-crossing' (Valentine, 2003) where they are adults physically and chronologically but emotionally still firmly bound to their immediate family for emotional and psychological support. Their experiences could not be reported without reference to the impact on and support of the family/significant other. A visual representation of the four super-ordinate and 12 sub-themes can be seen in Figure 4.1 and these are discussed in more detail as the Chapter progresses.

Figure 4.1: Super-ordinate and Sub-themes – A Visual Representation



Table 4.2 illustrates the recurring themes and indicates whether the super-ordinate theme is present for each participant. Although negative case analysis was considered for Helen and Stuart, as they were the only 'couple' in the study,

it is not commonly seen within IPA as the sample is ordinarily homogenous with the objective of finding a shared thematic understanding from the participants (Smith et al., 2009; Willig, 2011). Negative case analysis involves searching for and discussing elements of the data that did not support or contradicted patterns that emerged from data analysis (Polit & Beck, 2010). However, following the rigorous double hermeneutic circle approach and searching for the shared experience, it became apparent that this was not what I had uncovered. During data analysis, similarities in their experiences of living with MM were interpreted as being shared with other participants, and therefore this was ruled out.

Table 4.2: Identifying Recurrent Themes

Superordinate Themes				
Participants	Is It Serious?	Too Much Too Young	Not the Same	A Time to Live
John	✓	✓	✓	✓
Eve	✓	✓	✓	✓
Paul	✓	✓	✓	✓
Anna	✓	✓	✓	✓
George	✓	✓	✗	✓
Richard	✓	✓	✗	✓
Patrick	✓	✓	✗	✓
Terry	✓	✓	✓	✓
Helen	✓	✗	✓	✓
Stuart	✓	✗	✓	✓

4.2 Key Findings – Telling Their Story

For the purposes of this Chapter, the super-ordinate and the sub-themes are discussed along the continuum order of the cancer journey to provide transparency and natural flow to each journey. The exact sequence and timing of each individual cancer journey may vary, but all follow their inherent logic, with a beginning, middle and end. I have opted to illustrate the experiences of YP against the continuum of their MM to aid the reader in understanding the journey and the perceived lifeworld of each individual. Within the study, the findings were reported

utilising the idiographic and the double hermeneutic approach as required by an IPA methodology and a reliable co-creation of their stories.

To begin, I revisit the first step of their journeys, when each participant was living their everyday life and going through their mundane daily routine when they or others came across a change in their mole. Recognising that the mole had changed and required attention, waiting for this diagnosis through to the impact of the diagnosis was a significant part of living with MM and beyond. I have chosen to present individual participants and/or dyad per sub-theme, keeping to the idiographic nature of IPA, which in turn presents something unique to the particular participant and overall experience. By limiting the number of quotes to illustrate the themes, it ensures that the researcher is fully immersed in the data analysis while at the same time being interpretive of the participant's stories.

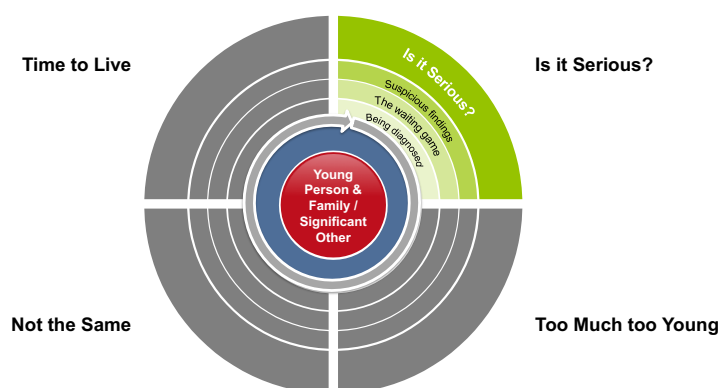
To assist in the identification of the individual participants and their specific narrative, Table 4.3 highlights the colour coding approach that has been adopted:

Table 4.3: Participant Colour Coding

Young Person	Family/Significant Other
• John	• Eve
• Paul	• Anna
• Patrick	• Terry
• George	• Richard
• Helen	• Stuart

This colour coding allowed for the individual voices to be heard throughout the detailed analysis, which is a critical component of the IPA approach.

4.3 Is *it* Serious?



The title of this Superordinate theme reflects the beginning of a journey from discovering the mole or seeing a change in their existing mole(s) through their regular daily routines

such as bathing or going to the hairdressers. This discovery caused initial bewilderment, with the YP wondering whether the mole was serious or not, followed by the worry in waiting for further information to finally being shocked when the confirmatory diagnosis finally arrived. This experience for most was long and traumatic. Many of the participants were uncertain and not sure what this change in their mole meant, but continued to worry. It was difficult for them to find support from either their GP or Dermatology clinic. However, when the mole was removed, and the diagnosis received, they felt shocked and frightened about how they were going to cope with the disease. Although the YP all had family/significant others to support them and protect each other, they also felt alone and isolated.

The question 'is it serious' was asked by all the participants at an early stage, and represented the beginning of their emotional journey through MM. This theme had three interrelated sub-themes that were common throughout most of the participant's narratives: 'Suspicious findings...what is it', refers to the YP and their family/significant other noticing the change in their mole; 'The waiting game' refers to their numerous GP and other appointments before being taken seriously; and 'Being diagnosed' which refers to being told that they have skin cancer. It became clear why the participants have referred to the mole as '*it*' as we move through this Chapter, and the participants' stories unfold to illuminate each of the themes.

4.3.1 Suspicious Findings.... What is *it*?

Feelings of bewilderment and confusion about the symptoms which they or others had found were present in all the participants' experiences. Most of the YP had

either noticed their mole had changed in shape and size while bathing or going to the hairdresser. This was the beginning of their journey of noticing worrying symptoms and wondering whether *it* was serious or not. This was common across all of the participants, and most were able to provide vivid descriptions of the changes in their mole but were unsure about its seriousness or potential impact. These participants were going about their daily lives when they came across a change in the mole. This initial discovery for most of the YP was relayed to their family/significant other and action was taken by arranging to go to see their GP or be seen at a Dermatology clinic.

Paul was 23 years of age when he described his experience, although he was first diagnosed with MM at the age of 21. He had lived with two reoccurrences of MM up to this time. He was an only child and lived at home with his mother, Anna, who was separated from Paul's father. Paul's experience was different from the other participants as he had lived with severe acne all his teenage years. He had grown a beard to hide his acne and therefore had not noticed the mole growing underneath. Paul's acne was being treated with medication which had serious side effects, most notably depression and he often felt suicidal. He was not sure why the Dermatology clinic had not noticed the changes in the mole first, before anyone else. While shaving one day, he had come across the mole under his beard and had recognised that something was not quite right as the mole was red and appeared to be growing.

"well I normally had a beard, so it was covering up the mole that was red and growing, so I'd never really noticed it before, but I'd notice while having a shave, so I was like 'what am I meant to do with this?'"
(Paul)

Despite his beard, Paul had noticed that the mole had become inflamed and was larger than usual, but he was not quite sure what to do. His bewilderment and recognition that these symptoms were worrying/out of the ordinary are seen in his comment "what am I meant to do with this?" This was his first time noticing the changes to his mole. Paul went on to describe what he did next:

"I've been coming to this building (Dermatology) since I was 12 or something, so you would think they would have noticed, well I normally had a beard, so it was covering up the mole that was growing.' I had an appointment coming up with Dermatology, so I waited" (Paul).

There were three telling aspects of this experience. Firstly, Paul was receiving long-term dermatology treatment for his acne and expected that the specialists should have noticed the change in his mole at an earlier stage. Secondly, finding the mole while shaving had prompted him to remove his entire beard to take a closer look. On closer inspection, it became clear that something was wrong with the mole. Thirdly, despite his initial concern about the mole, Paul opted to wait until his next routine dermatology appointment, some two weeks later, before raising his concerns with any of the specialists.

Anna, Paul's mother, also recalls the first time her son noticed the mole and related this to his long-term acne. What Anna remembers is that Paul was not sure if this was anything to worry about, and again, she thought it might be related to his ongoing acne. The uncertainty and ambivalence about whether or not there was something to worry about are reinforced here by Anna, and this seems a common part of the related experiences for both mother and son.

"At first, I thought it was his acne because he had got bad skin, he thought it was just his skin, an old spot, you know, but when the beard was off you could tell it wasn't quite right" (Anna).

It also appears that Anna was uncertain as initially, she had associated this with everyday acne spots. Similar to Paul, Anna also realised that the mole did look suspicious, especially once the beard was removed and they both could clearly see the mole. Again, there was an emphasis on uncertainty and ambiguity of whether or not there was something of concern. From Paul and Anna's accounts, there was a growing concern and worry, although they are still not sure what they had found. Two weeks passed, and they both describe what happens next after

the initial visit to the Dermatology clinic. Here Paul sees the specialist by himself, while Anna sits outside.

"So, they had a look at it and then cut it out, so by that time I was very, I was down a lot, and then cancer came along and I was like, I just kind of felt like initially, like I don't know what I am going to do, it just made everything a lot worse. But then, that one was just Stage I. So, after that, it was fine" (Paul).

Paul's first encounter with his Stage I happened when he was already emotionally depressed and at a low point in his life. The acne medication he was receiving had contributed to his depression, which made the MM experience far worse. However, the mole was excised, and life went on as usual, and his mother's comments confirm Paul's recollection:

"Anyway they removed that and we got over that quite quickly and life went on and then next minute he's going 'I think I got a lump' and I felt it and I can't feel anything and then it came up and then again, we knew exactly, I looked at the Internet, everything was pointing at it coming back again" (Anna).

The shared first experience between Paul and Anna was significant in that they seemed not to be very worried. From Anna's account above the mole was excised and all appeared to be well, it was over and "life went on". This experience continued for a further six months until another episode arose when shaving, Paul found a lump in his neck, but this time it was more sinister. Worry set in for them both. This experience was building up to a significant interruption to both their lives. They both knew exactly what it was, and they allude to this here. Underneath the veneer of a positive outlook, there was a foreboding feeling building. Anna's worry prompted her to search the internet for answers to what she was suspecting. The lump seemed to protrude from his neck when he swallowed, and Paul descried this lump as being "*massive*". Here Paul talks about the lump rather than the description of the mole itself:

"I had a shave one day, and my mum hears 'oh shit' and then she says 'what's wrong with you?' 'This lump is pretty big mum!' That was a little bit of a shock, seeing how big it was, it wasn't that large, but when I swallowed it popped right out'... so by this time, it was growing massively; I was like 'it's obviously back'" (Paul).

Paul was experiencing shock and concern over the size of the lump he had found. By calling out *"Oh shit,"* he was describing his sudden shock and calling for his mother to come and see what he has found. His mother hears this and rushes to the bathroom. They are both now aware that the disease had returned, but this time it was different as it was a "huge lump" in his neck. Once again, feelings of foreboding are coming through, that something was seriously wrong, but they are not sure what. What was apparent at this stage is that neither Paul or Anna are using the words MM or cancer, and this was common throughout all the experiences and is highlighted here through Paul's story.

Paul and Anna initially describe that they were not so worried about the mole, nor were they sure if the mole was cancerous. However, when the disease spread to the neck, they became distraught. This was where all the participants highlighted that there was a gradual transition to growing concern. The change from mole to lump was common in most participants. All had a second or third reoccurrence and went on to find a lump rather than a change in their mole (i.e. MM had infiltrated into the lymph system, and the disease had spread). This was a collective experience for most apart from one young man, John, who had one occurrence and was treated for this. Along with feelings of suspicion, there were similar emotional and physical changes described by Paul and Anna, which shaped the journey of living with this disease.

George and his father **Richard**, who shared their experience as a dyad, had a similar story to Paul and Anna. George was 21 years of age when first diagnosed with Stage III MM. He was 23 years of age when interviewed. George, like Paul, had not initially noticed the mole as it was at the back of his head, hidden by his hair. He had lived most of his life with moles and had not noticed any changes. For George, going to his hairdresser for his routine haircut was how the mole was

found. The hairdresser was worried by the mole's colour and the fact that it did not look quite right. Because the hairdresser was worried and had mentioned the mole to him, George was prompted to make an appointment with his local Doctor straight away. George and Richard did not delay and immediately contacted their GP for an urgent appointment. This was a similar reaction for all the other participants, apart from Paul.

"I was off getting my haircut, and my hairdresser went 'that mole doesn't look right'. So, I made a Doctor's appointment just to get checked, but it had got bigger, it had gone black and was all horrible, and they weren't happy with it, they weren't sure about it because it's only just a little local Doctor.' I would say, if it wasn't for my hairdresser spotting it, I wouldn't have noticed it, because it was round at the side there and I don't see it" (George).

Knowing that the hairdresser was worried, although vague in her description, it was enough to concern George. He was so grateful that his hairdresser had spotted a change to his mole as it was impossible for him to check the back of his head. He had been worried enough to make an appointment straight away. Although George's local Doctor was unsure and did not appear to be experienced in skin cancer, he decided to remove the mole and send George for further investigation. Initially, neither George or Richard expected the GP to take their concerns seriously, but the rapid removal of the mole instilled confidence in the Doctor and his skills. Both were relieved that the Doctor had removed the mole so quickly. Being listened to, and taken seriously, was a positive outcome for them both which was not shared across most of the other participants who had numerous visits to their GP before the mole was eventually removed.

"The GP kicked it off, and I would say, was exceptionally good. Well, we made the initial appointment for him, who's from the same part of the country as myself, he said 'aye, just send him up and we'll take it off and send it for analysis' and by the end of the appointment, he suddenly had four doctors standing about him saying 'we're no

touching that' and at that time, it was downhill all the way after that"
(Richard).

The father shares his worries with the local Doctor about the mole. This was similar to Paul and Anna's experience, although in this case, it was the father alone discussing his concerns and worries with the Doctor. The father feels he was listened to, and that action was taken. It was apparent that even the local Doctor knew that the mole required attention and that they would need to be referred urgently to the skin specialist. This local Doctor was not an expert in skin cancer, nor was he sure it was cancerous, but as it looked very suspicious, he removed the mole. Once again, this ambiguity and feelings of foreboding were building.

In following the interviews through, I was keen to know if the moles had been painful or had caused some discomfort and wanted to know if this part of their experience prompted them to examine their mole? I also wondered whether this had delayed finding the change in their mole. I asked George:

"Was the mole causing you discomfort, was it sore?" (Interviewer).

"No, it wasn't sore; it never bothered me or anything. And they weren't sure what it was, so that same day they said 'oh, we'll cut it off' because they can do that down there. So, they took photos of it, and they asked if they could use it for teaching students. Because they didn't know what it was, I said 'aye, that's OK. Everybody's got to learn'. So, they took it off, got a couple of stitches, and I was back to work the same day. And, I think it was a week later, I got, well, I was getting checked up after that, and they phoned me, and they said, 'we'd like to see you'" (George).

There were no painful symptoms from the mole itself, which was familiar to all the other young male participants, but there were changes to the colour and size of the mole. Professional uncertainty and ambiguity about the mole were also present throughout the participant's accounts, which mirrored the initial uncertainty and ambiguity experienced by participants on first noticing their symptoms. George was very matter of fact and was able to return to work the

following day, resuming his normal life, until he received the urgent phone call that changed his experience as Dermatology wanted to see him straight away. From this point, he was monitored closely as the disease can spread rapidly throughout the body.

At one appointment, the specialists felt a lump in his neck, and a biopsy was taken to determine the nature of the lump. This was George's second recurrence, and again, like many of the other participants, the disease has infiltrated into his neck. The disease had spread into the lymph, which is a common consequence of a delay in diagnosis. The second sub-theme, 'The waiting game,' explores the emotional and psychological impact of waiting for a diagnosis.

4.3.2 The Waiting Game

This sub-theme, 'the waiting game', summarises the numerous and repetitive visits back and forth to the GP and the Dermatology unit. This captures the experiences of waiting for an appointment, being seen and then the feelings of anxiety while the GP or Dermatology specialists delivered the biopsy results. Although the young participants reported that they did not feel ill, unlike many other patients with cancer, waiting for the GP to take their concerns seriously or to see the specialist seemed like an eternity. The waiting magnified the uncertainty and worry, which started at the point of discovery and was now prolonged until the point of diagnosis. This waiting for the initial diagnosis ranged from one to ten weeks. Apart from George, who had his mole excised immediately, all the participants had to wait before their moles were investigated. In the minds of each participant, the time taken for the initial diagnosis to be made seemed to be unending. However, after the diagnosis was made, the subsequent treatment seemed far speedier.

During the waiting for a referral and for a diagnosis to be reached, each participant felt helpless and fearful. There were two telling aspects about this sub-theme which are highlighted through John and Eve's experience. Firstly, 'not being taken seriously initially', and secondly 'feelings of relief and their suspicions being validated' before being referred to a specialist. **John** was 16 years of age when

his mother, **Eve**, first noticed the raised red spot on his neck. John was in his sixth (and final) year at school and looking forward to his future. John was the only participant who was diagnosed with Stage 2B, as defined in Chapter 1 and had no reoccurrence. Eve, his mother, was a nurse, and she was the one who spotted the change initially. John, like Paul and Anna, had presumed the initial symptoms were due to age-related acne/spots although his mother was worried about it:

“My mum was a bit more sceptical about it. But, throughout, when the mole came up on my neck, I, stupidly, just thought it was a spot, I thought I was at that age and I just thought, oh no, I am starting to get spots, so I was putting things like Sudocream on it, it was a tiny bit raised and the circumference of it started to increase slowly and we’d been back and forwards to the Doctor and they had assured us it was OK and that was down at my local GP.” (John).

As acne is more common in teenage boys, John had thought the change in the mole was typical of his age and was applying a cream to clear it up. In describing this initial finding, John describes how he ‘stupidly’ continued to apply a cream as if nothing was wrong. Eve, John’s mother, was correct in her more pessimistic view of the situation, perhaps because of her professional training as an adult nurse. They had attended the GP on numerous occasions, and although John initially was not as worried as his mother, they were eventually referred to the Dermatology clinic. After a few visits to the GP, they were told that all was fine. As the Doctor suggested that all was fine, they decided to go on holiday, although growing worries about the changes to John’s mole continued to nag his mother:

“So, we went to Tenerife, I kept worrying about it, and I kept staring at it while we were on holiday. And I kept thinking ‘that’s getting bigger’. And I thought ‘oh, I’m not happy’. So, the whole holiday I was like, ‘when can we go home?’ And the day we got home, we flew in really early in the morning, and I had stayed up to call the Doctor at 8:30 in the morning, but I had to be somewhere that day, and so I said to my husband would you take him to Doctor. But I don’t want

you to leave the GP's without an appointment, an emergency appointment for Dermatology" (Eve).

Eve was unhappy for the duration of the whole holiday and knew deep down that something was wrong. Experience had taught her to keep an eye on the mole (as a nurse). Eve was desperate to get home and seek professional advice as the mole continued to grow and change throughout the holiday, suggesting that something sinister and frightening was afoot. On returning home, an urgent appointment was made to try and resolve her fears. A sense of urgency was present here and desperation to get help. This time when they attended the GP, they saw a different Doctor who again was not worried, but as John and the father insisted, they were referred that day to Dermatology:

"So, I was like 'six weeks, that's actually not very urgent!' So anyway, six weeks came and went, and we came up here, and we saw one of the consultants here, (Dermatology) who again said he didn't think it was anything serious, they thought it was a basal cell melanoma or whatever. So, they said 'we'll take it off, anyway', but patted him on the head and said don't worry, they were not really taking the mole seriously but took it off anyway. So within about four days, we got a phone call saying you need to come up, and I just knew then that there was something wrong" (Eve).

John had to wait six weeks for his appointment with a specialist. For Eve, the wait for the appointment was particularly slow and arduous and compounded her feelings of inadequacy through her perception that the doctor was not taking her seriously. There was also a growing realisation within the family that their concerns for John's health were not seen as urgent by the specialists. When they were eventually seen again, this sense of not being taken seriously was confirmed in Eve's mind. The dermatologist claimed not to be worried about the mole and suggested that it could be a melanoma but not the sinister type (MM).

In Eve's account, the specialist was presented as being quite dismissive and patronising through patting John on the head as if he was a child with unrealistic and unfounded worries. In reality, John was worried as he described:

"Because I had been assured by others, who I saw as professionals and I thought, and you trust your Doctors. So, at my GP I think that was the thing from the start, prior to any diagnosis I was pretty chilled about it, and then when I came up here (Dermatology) to get the results, they do a small excision to take out the mole, and I was fine up till then, and then we got the phone call, which it was a bit early, so we had been waiting ages and then it was like we need to see you" (John).

Before his MM diagnosis experience, generally, John had a high degree of trust and respect for the GP and the healthcare profession. This, however, was shattered by the urgency of the call after waiting such a long time for an appointment.

The key message from this analysis was John and Eve's disappointment at the lack of respect for their concerns about the mole and the time taken to achieve anything. This apparent indifference exacerbated their worries when the urgent and 'sinister' call was received requesting their immediate attendance at the hospital. This experience may have shaped subsequent experiences which follow in this journey.

Recognising early changes in the mole was seen as crucial to their lived experience, but for some of the participants like John and Eve, it resulted in a long and anxious waiting game. The journey quickly became very intense for both the young person and their family/significant other with the sudden change from being reassured by health professionals/doctors to receiving pressing phone calls and needing to be seen as a matter of urgency. What was suspected and significant here although not yet spoken – that this was a serious situation.

Helen was diagnosed with Stage 3 MM on her abdomen at the age of 25 years of age and was 26 at the time of interview. Helen was the only female participant in this study, and she was the oldest YP who had lived in southern Europe most of her life. Helen had grown up in the sun, with moles all over her body and had been vigilant in checking them daily, throughout her life. It was evident that Helen was fully self-aware about her life and the moles on her skin. Helen was interviewed as a dyad with **Stuart**, her significant other. Helen – similar to George, but not Paul or John – had grown up with many moles all over her body but had checked herself every day. When she noticed that one of the moles on her abdomen was causing her discomfort and had changed, she knew that something was wrong. Up until this point, they had not changed, but she had always tried to avoid over-exposure to the sun. This was seen as a way of life for Helen and her family. When she identified that the mole had become red and tender, she immediately knew there was something wrong. Stuart, her partner, was aware of the change and knew Helen had gone to her local Doctor who then referred her to Dermatology. Helen and Stuart waited the longest time for a diagnosis to be reached, some ten weeks. Stuart, her partner, was not mentioned here as he initially was not part of this first experience for Helen. Although he knew she had concerns, she did not elaborate on these or want to worry him. Helen was protecting Stuart, which was another critical aspect of this waiting phase. Many participants seemed to be fearing the worst but also trying to protect others from thinking about it. To highlight Helen's experience, there were three key aspects to her journey to reaching the diagnosis; 'recognising something was wrong', 'protecting others' and 'waiting a long time to be told.' To start, Helen described the mole on her stomach, which seemed to have been bothering her for a few months:

"It had become sticky and bleeding, and sometimes it was painful. This has never happened in my life before. Last year I started to have a problem with the one on my stomach, I was born with moles, and it was already big and always flat. It was not any problem, never bleeding, never itchy. But it was one year and a half ago it was sticky and bleeding sometimes, and it was painful, which has never happened in my life. So, I went to the Doctor, to say it was bleeding and I knew that was not a good sign when a mole is bleeding. So, I

came to the Doctor she gave me the first out-patient appointment to the Dermatology" (Helen).

Helen's mole had begun to change and cause her discomfort. Within this extract, she vividly describes how her mole has changed and the discomfort she experienced. Helen knew this was unusual and required immediate attention. The mole was not how it should be, and she was worried, as seen in the narrative above. This prompted her to go to her Doctor. The Doctor also realised that the mole had changed and that a specialist should see her. This follow-on appointment with the specialist seemed to be made quickly, and Helen was then seen straight away.

"What were your thoughts about the change in your mole and having to wait for the results?" (Interviewer)

"After I spoke to the Doctor and she said 'OK, we'll just remove it because I'm not sure what it is so, you don't need it so we will just remove'. I removed after I came back from holiday in November, it was the 26th of November, and everything was fine, those stitches were most painful because it was just a local anaesthetic, the scar was just quite big. I had to wait, they took the biopsy, and they would call me. And actually, two and half months passed and then they called because they weren't sure what it was" (Helen).

Helen was reassured when the mole was removed, although it left her with a large scar. However, they had to wait ten weeks before they received a call from the specialist, as mentioned earlier. This was particularly long as others waited between days and a few weeks. Again, this brought about uncertainty and worry. For Helen and Stuart, the waiting for the biopsy results seemed exceptionally long. This waiting was draining for both Helen and Stuart, and although they got on with their daily lives, it was continually at the back of their minds.

"And actually, two and half months passed and then they called because they weren't sure what it was. And they were asking 'we need to check, or we need to wait and see how it grows' I don't know

how they do it. I had a couple of examinations, and they identified two lymph nodes, one here and one here (groin and axilla). And they would remove when I had the first surgery, so I just waited. The first surgery was in March (2018)" (Helen).

Initially, it would appear that the Dermatologists were unsure of Helen's diagnosis. They had removed the abnormal mole but had decided to wait and check her regularly, which is a similar situation to that faced by George, who was also being regularly checked. However, the delay between removing the mole and further surgery was lengthy, for Helen, and it is not clear why she had waited so long. This time-lapse brings this uncertainty and worry about what they might find in the minds of the YP. Similar to all the other young participants, the disease had infiltrated into their lymph system, and surgery was now required. For some who experienced a second and third relapse, more surgery and treatment (immunotherapy) was also a requirement for them.

The hidden "it" as described by participants becomes the present threat in their lives, building upon the uncertainty and the worry until their suspicious symptoms are finally identified as Cancer. How the diagnosis was communicated and received is discussed next. The issues of trust and respect for the healthcare professionals by the participants was described, which builds upon the period of uncertainty and prolonged worry. This was the next part of the journey which left them in disarray, uncertainty and fear. They were left feeling unprepared although they had suspected that there was something wrong with their mole.

4.3.3 Being Diagnosed

The initial MM diagnosis involved a delay for the majority of the participants. Time spent waiting for a diagnosis ranged from one to 10 weeks, depending on where the participants were located. The treatment to remove the initial mole was either by a small excision carried out in the GP Surgery or Dermatology department with further excision of the disease, if it had spread, following hospital admission. At this point in their journey, participants could recall being told that their 'suspicions' were related to 'melanoma' or 'skin cancer.' How this news was communicated to

the participants was also relevant, as most were left confused and required more information. The majority of the YP had never really heard about this disease and most did not associate it with 'cancer.' Many believed that cancer carried a stigma, but this was a perspective riddled with many misconceptions. Most of the participants had to live through the experience of receiving bad news more than once. An aura of normality that had paved the road ahead for these YP had instantly vanished when they entered the room to receive the news. As they left the room, they could recall the realisation that their world would never be the same again, and their lives had changed forever. It appeared that the emotional suffering did not stem from the diagnosis itself, but the impact on those around them, such as their mother or partner, and the profound effect cancer was going to have on their lives going forward.

Many of the participants felt disappointed by how the diagnosis was communicated to them. The environment and the way the 'news' was given was troublesome for the YP. Most had gone into the room with their parent/partner. John described how he was informed that he had MM:

"I came into the room, and they said, it's a melanoma and I didn't know what a melanoma was at the time. So, when I said 'what's a melanoma?', they said 'you've got skin cancer' and then that, I think as soon as I heard the word cancer, because it had such a stigma to it, it hit me like a ton of bricks at first" (John).

Despite his disbelief in the diagnosis, John was shocked when the word cancer was mentioned. He had never heard of melanoma, but he was aware of cancer. The impact of the word cancer so eloquently described by John as "hit me like a ton of bricks" effectively communicates the scale of the impact on John and his extreme emotional and negative reaction to the word cancer. This was compounded by the stigma John associated with cancer.

The evident suffering worsened John's emotional reaction, which was revealed on Eve's face at the time of the diagnosis. Eve was in the room with him as he had only recently turned 16, and he needed his mother with him.

"As soon as we walked in, I knew because there was nobody around, the place was dead quiet, it was like everybody had gone home, kind of thing. It was just us two, and then when we walked into the office, there was the consultant and the CNS, and I thought 'oh God'. And then I suppose our whole day just collapsed there. And then the consultant said 'I'm really sorry, but it's cancer' and of course and I just went 'Oh my God' and then burst into tears" (Eve).

Eve's experience was notable for several reasons. Eve had long suspected that something was wrong with her son, and even the atmosphere when she entered the room seemed ominous. Her instinct had told her something was wrong. After the diagnosis was given to John, Eve's world just "collapsed" in on itself. For Eve, her worst fears and suspicions had been confirmed in the harsh clinical light of the dermatology clinic and this released feelings of profound shock and distress within her. Both mother and son experienced these feelings in different and very personal ways, but the physical and emotional impact was profound for them both.

Helen and Stuart recounted a similar experience. During this part of the journey, they were together at the Dermatology clinic receiving the diagnosis:

"Well, I was actually kind of shocked, he was with me (Stuart) because we just entered, so there were these two doctors and they just 'OK, sit down', and I think 'OK, this is nothing too good if they are telling me to sit down'. So, we just sit, and she just gives me this book with Melanoma Cancer, so I was like 'we're talking about cancer!' and after she started to explain that it was a Melanoma, for the biopsy they just waited to see how it evolved and was a very aggressive stage" (Helen).

Entering the room with Stuart, Helen experienced a profound sense of unease that seemed to be originating from the two specialists waiting for her. Despite the detailed clinical description of her aggressive Stage 3B MM, the seriousness of the disease only became apparent to Helen when the word 'cancer' was first

spoken. It was this word that alerted Helen to the seriousness of her situation, rather than the description from the specialists.

"So, it was a bit of a shock when we were told that she had cancer' it was strange because you know, there was one doctor, that was very serious, and she was looking at us, like sad. And the other was like more upbeat'. For me, it was a bit of a shock, of course. Especially for me, because when we were told in January, that was the second person for me who I was close to who was diagnosed with cancer. So, it was a shock to me because I had lost the other person" (Stuart).

This extract seems to indicate that the specialist Doctors felt uncomfortable in giving Helen and Stuart the diagnosis and that there was safety in numbers by having two doctors present. It also suggests they knew that the true seriousness of Helen's disease at this time.

There was more devastating news to follow later that day when it was confirmed that cancer had spread to the lymph nodes within her abdominal area. This meant additional surgery for Helen along with immunotherapy. This treatment was unlike any other previous treatment, and as a result, Helen was required to attend a specialist centre some distance from her home.

Stuart was shocked and fearful for Helen. He had previous experience of a close friend dying from cancer. This experience had been quite recent and to learn that his partner had cancer seemed unreal to him, resulting in feelings of fear and shock. He had been looking at the Doctors for reassurance, but no such reassurance was offered. He was trying to read the signs before the news was broken, but this only caused him confusion. He felt total despair.

The narrative below illustrates how the young participants began to see the seriousness of MM and its treatment. Although Helen and Stuart, both 26 years of age, and the oldest participants in this study, their experiences of shock and disbelief were similar to the other participants.

"Yes, actually the last time I spoke to my Doctor he told me, because I'm high risk, they told me it was a very aggressive type of Melanoma which I had, and because there was already a cancerous cell in one of my lymph nodes, they just told me to do a kind of, it not a proper chemotherapy because they told me I not going to lose my hair or stuff like that, I actually don't remember the name" (Helen).

Helen's immediate reaction was to question in her mind whether she had a 'proper' kind of cancer. This reaction seemed to be based on the proposed treatment that did not involve chemotherapy. In Helen's mind, there was an association between the word 'cancer' and 'chemotherapy' as the only available treatment option.

Once the diagnosis was confirmed for all the participants, the subsequent weeks were just as challenging and emotionally fraught. However, although it was relatively normal for most people to think about having cancer and its impact, it was near impossible to articulate it to family and friends.

Participants described the disease as being different from other cancers as they did not feel ill. Most continued to refer to the cancer as 'it' even when they recalled their experiences through the interview process. They rarely talked about MM or cancer. Saying the words "*I have cancer*" or "*my son has cancer*" was extremely difficult for them. The possibility of death from the disease, in the near or more distant future, brought deeply rooted fears and uncertainty to the surface. This is explored further in the following 'Too Much Too Young' theme.

"Those days had gone. We went about accepting our new, redefined normality, and when we met in the hallways of my house, we all maintained the "I'm okay" mantra" (John).

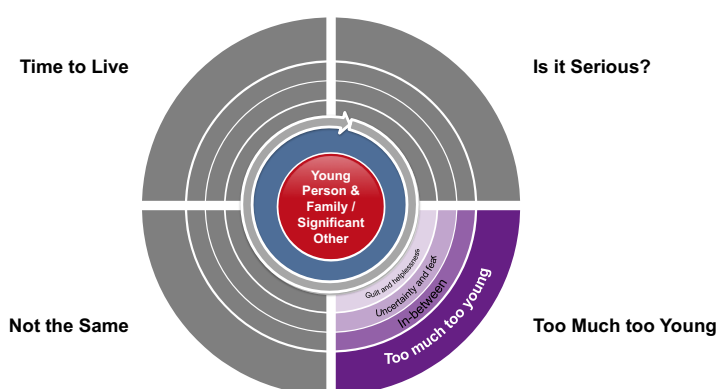
Day to day the YP and their families/significant others accepted this new re-defined normality. In this new reality, John's quote clearly shows the emotional need to retain the status quo of everyday life and trying to be positive.

4.3.4 Summary

This super-ordinate theme, 'Is *it* Serious,' explored the participants' experience of finding the mole and feeling bewildered and confused with what they had found. Irrespective of how the changing state of the mole was noticed, either through personal vigilance in the case of Helen or through the observation of others as with George's hairdresser, the delays encountered during the road to a confirmed diagnosis was long and arduous. These experiences emphasise the need for greater public awareness and knowledge about skin cancer. All the participants in this study confirmed that their understanding of the risks of skin cancer was minimal. This lack of awareness combined with the belief that 'it will never happen to me' can lead to even more significant delays in MM in YP being diagnosed and treated.

Even when the young person has decided to act and seek professional advice, there was a real concern that they would not be taken seriously. For many of the participants, this concern appeared to be well-founded with delays experienced in obtaining a referral to a suitable specialist, disjointed approaches to treatment, which resulted in feelings of fear, loneliness and frustration. Throughout the first and second theme, the YP referred to the cancer as '*it*,' and avoided calling '*it*' by any name. This first part of the journey was a fraught and difficult experience, although it was not always clear whether they had taken '*it*' seriously.

4.4 Too Much too Young



The second super-ordinate theme is 'Too Much too Young' and brings a deep understanding around the next part of the journey of how an MM diagnosis impacts on young lives,

physically, emotionally and psychologically and on their family/significant other. This theme is divided into three sub-themes. Firstly, 'In-between', which refers to not being a child or an adult. Secondly, 'Why – uncertainty and fear' which refers

to young people's lives changing through having MM, which also causes fear of the unknown. Thirdly, 'A sense of guilt and helplessness' where the family, in particular, feel they have not protected their child and are at a loss of how to support them in their time of need.

As discussed in Chapter 1, young adulthood is characterised by the creation of fluid power dynamics within the family unit. The young person frequently asserts some independence while continuing to rely heavily on the support of parents and family/significant other. When an MM diagnosis is added to this dynamic, some families reported that their child was not equipped emotionally or socially to deal with such profound news.

4.4.1 In-between

Attempting to understand and normalise their MM diagnosis while trying to live their lives was a complex challenge for the YP. Many found it challenging to move beyond the disease, and the younger participants began to realise that some aspects of life were no longer available to them. For example, being unable to complete a school career with the expected academic results and failing to achieve their full potential. Several participants reported a loss of innocence as the disease robbed them of their youth. For the family/significant other, their child/loved one required their love and care to protect them during these tough times.

Two telling key aspects were underlying this theme. Firstly, the sense of being 'In-between,' with the participant being neither a child nor an adult. Secondly, all of those affected by the MM diagnosis wanted to help protect one another from whatever life was about to throw at them.

Patrick was 16 years old when interviewed with his father **Terry** as a dyad. Patrick was 11 when first diagnosed with MM, and by the time of the interview, Patrick was enduring his third relapse (cancer has reoccurred). Patrick had missed much of his secondary education due to extended periods of hospitalisation. This was an unusual situation when treating MM, and as a result, his future academic

options were limited. The family unit had broken down, and the father, Terry, was the primary carer. Terry had lost his job when caring for and supporting his son through periods of hospitalisation. Simultaneously, Terry was struggling to care for Patrick's younger sibling. As they recounted their experiences, it was clear that Patrick and Terry's journey was unique in some aspects, but there was some commonality that related to all the participants, such as the tensions around independence versus dependence.

In the interview, Patrick found it difficult to share his experiences. He was only 11 years of age at the time of his original MM diagnosis and was not fully aware of the fact that he had cancer. He relied on his father to recall these events, and it was unclear if he could remember or if he chose not to, leaving his father to tell the story. Patrick seemed withdrawn but willing to share what story he could remember. During the interview, it became evident that Terry, in trying to protect his son, had never disclosed to Patrick his initial diagnosis of cancer.

The father began the story by explaining he had not informed Patrick of the cancer diagnosis because he was frightened that Patrick would be unable to cope with such a serious event. Although made aware of his cancer diagnosis during his second relapse at the age of 15, he was now experiencing his third relapse.

Patrick commented that he was grateful to his father for trying to protect him and recalled how his father knew about the diagnosis before him. It was unclear whether Terry understood the seriousness of this initial diagnosis. This is the only example in this study of the truth being withheld from the young person, albeit Patrick was a child at the time.

"He was a child, I told him he was only going in for a wee operation, to get something off his leg. And that was my decision to do that, and I've stuck by that to this day" (Terry).

Terry described the operation that was required to remove the 'wart' as "nothing to worry about." Terry maintained that withholding the truth about the diagnosis was the right decision and in the best interests of Patrick. He believed this to be

true even while the interview was taking place. Terry had no regrets over his actions. All the other participants were old enough to be informed about the diagnosis and accept responsibility for their treatment.

Patrick's mole had started on his upper thigh, and like all the other YP, apart from John, the disease had travelled in the lymph system. During the interview, Patrick's father, Terry, spoke the most, but Patrick didn't seem to mind this and looked to his father throughout for constant reassurance. When asked:

'How did you notice the mole?' (Interviewer).

'I have had that since I was a wee boy. It was like a big wart on that bit of my leg (points to his left thigh)' (Patrick).

Patrick described the mole vividly. He could point to the exact location on his leg and the fact that it resembled a "wart." He could also point to the scarring that resulted from the removal of his lymph nodes in his groin area. Patrick described that it had been there for a long time as if it had become part of him. Terry, his father, had noticed it also, and they both wanted to seek confirmation from their GP to find out what it was.

"We went to the GP, he was only 11 years old, well, we'd already been to the GP three or four times, about this. The first time we went back, it had got bigger, and the second time, we got knocked back, and it had come back bigger again. So, we went up to this same GP three times, got told 'oh, no, just a skin lesion, nothing to worry about. The fourth time we went up, the GP was on holiday and saw someone else; they want that seen to straight away and get that tested and that's when we found out" (Terry).

The father explains that the Doctor was often dismissive and failed to address their concerns and worries about the mole. Patrick, a boy of 11, was caught 'In-between' on many fronts. Firstly, he relied on his father to initiate and arrange the visits to the GP as Patrick merely thought that he had a harmless wart on his leg. His emotional and intellectual immaturity prevented him from seeing the more

serious potential. Secondly, the healthcare system did not adequately cater to their needs and Patrick was dependent upon his father and his persistence to ensure that their concerns were acknowledged. Thirdly, this 'In-between' status revealed itself when the results from the skin biopsy were relayed to Terry, rather than him. Patrick described how the news was given to his father and not to him:

"He told my dad, but my dad didn't want to tell me because he thought it would worry me, and if my dad thinks it was the right decision, then it was" (Patrick).

Sometime after the mole had been removed in an adult hospital, that had no specific provision for children and young people, Patrick then noticed a lump in his groin area and told his father.

"It was only a wee lump, and again we were told, don't worry about it, it's his age, and then the next thing is we are going back up six months later" (Terry).

Terry was now angry that once again his concerns around Patrick's health were being downplayed and disregarded. Terry recalled how his concerns were not heard the first time around, and he felt powerless to stop the same situation arising again.

Patrick and Terry had a strong connection with one another and a mutual dependence that was obvious and visible. It was unclear whether the healthcare professionals initially believed that the lump was due to his age and stage of development or whether they did not know. Six months later, Patrick was seen again at a specialist children's hospital, and further treatment was required. It was this episode that represents the significant interruption in family life for Patrick and Terry. This was the point when Patrick started to miss school on a regular and frequent basis. Travelling to and from the specialist hospital for treatment was often lengthy, expensive and complicated for the family.

During their experience of MM father and son had become inseparable, with Patrick dependent upon his father. Consequently, his father had become the most important person in Patrick's world. For Terry, he went on to describe:

"I needed to watch him, and that's why I lost my job' and 'it's hard to remember this, in order. You've got to remember, when he went through all of this, he lived with us for one month out of six. So, my memories are all over the place with these times and places (Terry).

Terry's primary role as a father, carer and friend to Patrick was putting extreme pressure on the family unit in a serious way. Terry was present with his son in the hospital where they spent the next five months as Patrick had become seriously ill from the treatment. This placed a considerable strain on the family and his father. As Patrick was under 16, Terry was responsible for caring for his son with only limited support from extended family and friends. As Terry was devoting such time to caring for Patrick, he could no longer manage his full-time job. Trying to remember these events was stressful for Terry and his memories are blurred and confused.

4.4.2 Uncertainty and Fear About the Future

After diagnosis, trying to accept that they had the disease and move forward with their lives, participants were able to describe the uncertainty and fear that the diagnosis brought. The true scale of the MM had been revealed, all their suspicions and worries unhidden but now turned into the unsaid with internal fears and worries about the future never fully or directly expressed.

Part of this theme concerned the uncertainty and fear of dying from the disease, like other patients with cancer, they had become aware that death was a possibility. The stark change to their previous thoughts about MM had now become a reality that could possibly happen. This was where the ambiguity and worry became real and true for some of the participants and trying to comprehend what this meant moving forward with their lives was very scary.

There were two key telling aspects to this theme, 'uncertain futures', which refers to their lives being turned upside down, and 'fear of the unknown' which refers to being frightened of what might happen. John had previously experienced one occurrence of the disease, and in contrast to all the others, he still felt his future had become uncertain.

"who wrote this into my life plan. I was diagnosed when I was 16, so that was the start of my sixth year at school, so I took a bit of time off from school, then I think I was diagnosed on the 21st of October and I think I got the all-clear towards the start of December, so it was a pretty short period of time although it didn't feel that way " (John).

This account highlights the significance of John's life being interrupted by the disease at this period in his life. John was fully engaged with his school and academic life and dealing with the ordinary emotional journey of being a teenager. John can clearly recall his story from the time he was initially diagnosed to the specific month when he received the 'all clear.' The disease had caused significant emotional turmoil in his life, creating considerable uncertainty about his future. He further explains;

"When you are 16, people say to you all the time, and I don't even like saying it myself, but you think you're a bit invincible and I didn't think that I was invincible but to an extent I did, I thought really bad things like cancer don't really happen, they don't happen here" (John).

Within this narrative, John described how he was only 16 years of age when cancer came along, and he was surprised that this had happened to him. Being young often brings a belief of immunity to such illnesses and that cancer does not happen to YP who are looking forward to their futures. At this age and stage, YP believe they are unbeatable and can conquer anything life throws at them. This was precisely what this young man and most of the other participants felt and experienced. Adverse life events happen to other people; it was often difficult to

accept that this can happen to anyone. For John's mother Eve, this was also a surprise.

"At 16 they are making choices about subjects and University. I had hopes and dreams of what he would go off to do at University and study, and suddenly your life is sort of on hold" (Eve).

The pervading feelings of uncertainty and fear also affected the family in the present and their possible futures as this mother illustrated through her narrative. While Eve was sad for her son, she too had hopes and dreams that were suddenly changed, and her life became dependent upon their MM journey.

In addition, this mother, like many of the other families, believed that their child had been robbed of their youth. The disease had taken their child down a different path from the one they had envisioned. The cancer arrived at a fundamental crossroad in the lives of the YP when they and their families were in the process of developing and supporting early adult life plans. This was the point where the participants now realise the seriousness of this disease and what this could mean for their lives. For some, the future was difficult and frightening to imagine.

"It was like being on an emotional roller coaster the whole time, and I could not get off" (Eve).

Eve's experience described through the roller coaster metaphor evokes the sense of emotional turmoil and lack of control that she was struggling to cope with. The highs and lows of coping with John's MM and the unpredictability of how the disease would manifest itself over the next few months were very draining for Eve. Often, she would find herself in despair over the fear, uncertainty and unpredictability around John's future. At other times, she would be filled with an optimistic view of John's life prospects. Underlying Eve's comments was a powerful sense of resentment at the loss of control over her life and its circumstances. Ever since John's MM diagnosis, she had found herself on a track not of her choosing and with no real influence over what would happen next.

Being able to articulate their fears about the cancer and discuss them with family and friends was cathartic for the YP and their family/significant other, although some reported that they found it difficult to say the word 'cancer'. For all, these early conversations were the most emotionally challenging and uttering the phrase 'I have cancer' would ultimately end in tears. For the YP to know and accept that they had an aggressive form of skin cancer was an integral part of their journey, especially for those who had metastases (MM which had spread to other parts of the body).

The YP all reached out to the available specialist support services at a time that was right for them as individuals. In many cases, the first and most immediate support came from the Clinical Nurse Specialist (CNS).

"At the time, it was relatively easy to think about it but near impossible to articulate it. Saying the words "I have cancer," but Mary (CNS) was fantastic from day one, absolutely unbelievable; I couldn't say a bad word about her. She just said you are a very sensible young man, fit and strong. I joke with her sometimes, because she was like a second mum. Whenever there were, questions that either I didn't want to say to my mum or maybe I had a fear that she would take it the wrong way, I knew that she was right there. And she was always very good at easing any queries that I had or any, even things that I couldn't say myself, she would make it clear and that would sort of ease the pain for me. Because at the time I was very physically fit, but skin cancer is one of those mental battles where you think I got cancer, but you can't really feel it, especially if you catch it early" (John).

John, like the majority of the YP, expressed their admiration and gratitude for the CNS, who was a source of support during this time of uncertainty and fear. They all had experience of the Skin CNS for MM, and this was the healthcare professional who provided the most support and advice. For some, the CNS became a surrogate family member and would predict what kind of support or advice was required without the young person having to say it. The CNS lifted the

family's burden and supported them in maintaining a balanced but positive outlook. John, who was physically fit at the time of his diagnosis, found the challenges to his mental health presented by the MM far more significant than he anticipated. This experience was quite different from other cancers such as Lymphoma, which can be a ravaging physical and mental experience for patients.

In addition to the information provided by the CNS, some family members and friends wanted to know as much as possible about the disease and used the internet as a resource, but with mixed results.

"I just, I stupidly, started reading about melanoma online, and I'd been told not to do it, but I did, and that made me worse. I thought 'oh my God, he's going to die, and he is not going to survive five years, he going to be dead by the time he is 20'" (Eve)

Attempting to understand and find out more about MM was a necessary coping strategy for families. However, the scope of information available via the internet merely confused and added to the fear and uncertainty being experienced by the family members. Without anyone to explain or interpret the information, or how it could apply to their child or partner, the unfiltered information heightened their sense of panic and caused them to worry uncontrollably.

4.4.3 A Sense of Guilt and Helplessness

Following on from the 'uncertainty and fear' of living with MM was an overwhelming sense of 'guilt and helplessness' on the part of the YP and their family/significant other. The YP felt guilty as they were not ill unlike other cancer patients, but they had started to realise the seriousness of the disease. In contrast to the family/significant other, the YP expressed guilt around having to rely on their parents or loved one to support them. Young people described how this interruption to their lives had placed heavy emotional strain on their immediate family and friends. In contrast, the families felt guilty because, in their minds, they had failed to protect their child from the sun and blamed themselves for the disease. The feelings of guilt and helplessness were helped by the support

available from the CNS. However, the support available from other healthcare professionals was not always available or consistent. Some families commented that they felt alone with almost no support to help them make sense of the situation they found themselves in. For some, the existential questions of “why has this happened”, and “how will we cope?” were common, but the answers were not always readily available.

"I could not make sense of why he had skin cancer, he was never in the sun, and he never got burnt as a child 'why should this happen to him he has done nothing wrong" (Anna)

Anna expressed her disbelief in the fact that her son, Paul, had this disease. She questioned why this should be as he was never over-exposed to the sun, never went to a tanning studio and looked after himself. In trying to understand her situation, Anna was seeking answers to why her son should have this disease. Anna felt helpless.

Another mother, Eve, described the situation differently:

"I just felt so guilty, more than that I felt guilty, that I had been a bad mother, and I'd allowed my child to get skin cancer. If you know what I mean, I was beating myself up about it every day, and I kept saying to everybody, 'it should've me' and I kept saying 'why is it him, it should've been me.' But I'm sure a lot of mothers, with a lot of teenagers or children say that" (Eve).

Eve's experience was different from Anna as she believed that it was her fault and blamed herself. Eve believed that she had not done enough to protect her child in his early years from this disease. Indeed, Eve went as far as to wish that the MM had happened to her rather than her child. She was aware that many mothers would feel this way, but that did not offer any comfort. Eve was traumatised by this experience and expressed overwhelming guilt and self-blame, making her feel helpless with no influence over the likely outcome.

The majority of the participants believed that this disease was related to exposure from the sun or sunbeds. Like the parents, the YP had tried to recall any overexposure to the likely causes of the MM. As John described:

“At the time I didn't do anything to abuse my skin, I didn't go on sunbeds or anything, and it can be just as simple as that, it can crop up. My mum always covered us in sun cream, I just want to take that shock away from some people, if ever did happen to them, because that's where I think my worry came from, we had done nothing wrong” (John)

Unlike his mother, John knew that his skin had not been abused and specifically did not blame his mother for any action or inaction that could have resulted in the disease. John's attitude seemed to be very phlegmatic and pragmatic about the disease compared to Eve's reaction. This was best illustrated in John's previous description under 'The waiting game' sub-theme, where he was very relaxed and at ease with his situation. This attitude was demonstrated as John tried to understand what had caused the disease within him. In this narrative, John appears to be saying that greater public awareness and knowledge about the causes of skin cancer could help people understand how this type of disease occurs. In some situations, the occurrence of MM can be almost random, with no visible link to UV light. As John further explained:

“When we went abroad, I covered up, and mum and dad were a bit paranoid about getting sun cream on us in the early days. So, I think that was, that didn't shock me, but it shocked mum, I think. I think she feels quite responsible still, and when she comes in to speak to you, she'll probably address that herself. But that's something that my dad's come to terms with; I think he's come to the point where he thinks 'this was pretty random, we did everything we could to help in the best way'. But I think being a mum she thought 'I've tried my whole life to try to help in every way, and this blip in the road is my fault' and it's not and to pin that blame on herself is stupid because we can't pinpoint where it came from, and personally I think it just

quite a random thing. Like I didn't expose myself to the sun any more than the person next to me" (John).

In direct contrast to John's experience was George. George could recall when he had exposed his skin to the sun and had been 'burnt.' He was 23 years of age but could recall this experience as a small boy:

"I'll admit when I was young, I was always outside my house always out on my bike and I never wore sunscreen, and it was always my neck that burnt first, and it still is, so that probably didn't help when I was growing up" (George).

George has never worn sunscreen even now he is a young man. His skin has been overexposed to the sun and has been damaged on several occasions. He understands that this may have contributed to his MM.

4.4.4 Summary

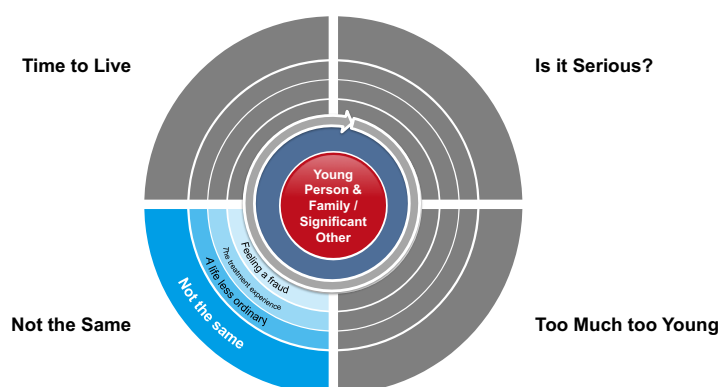
This super-ordinate theme, 'Too Much too Young' illuminated three subthemes 'In-between,' 'Uncertainty and fear about the future' and 'Sense of guilt and helplessness.' The concept of 'In-between' represents that time when the young person was neither a child nor an adult. Living with an MM diagnosis reinforced the YP's dependencies on their family/significant other just as they were attempting to assert some independence from the family unit. This dependence on support from the family/significant other extended across a range of different life situations.

The confirmation of the MM diagnosis also brought an overwhelming sense of the unknown into their lives. Earlier plans and ambitions had to be rearranged and postponed, replaced with the immediate priority of dealing with the emotional, social and physical impact of the disease. In looking for guidance, advice and support to see them through this challenging time, many participants reported a significant lack of support from the healthcare system. The notable exception to this was the references to the value provided by the CNS role, where available.

The YP were not physically ill and demonstrated a range of modest symptoms and as such, felt quite different from other people with cancer. Families/significant others blamed themselves for the disease and sought reassurance from other sources to understand why their child/loved one had to suffer in this way.

For many of the participants in this research, the term 'cancer' was pre-loaded with a social stigma and was commonly seen as synonymous with death. Fear of death was the rational and expected response in these circumstances for the YP and their family/significant other. For many, the stark reality of their MM diagnosis, contrary to their initial symptoms, had still to be entirely accepted and internalised, even though for some, this was their second or third recurrence.

4.5 Not the Same



Following on from 'Is it Serious' and 'Too Much too Young' is the 'Not the Same' super-ordinate theme. This third super-ordinate theme has been further categorised into

three sub-themes: 'A life less ordinary' which refers to adjustment and coping to the diagnosis? 'The treatment experience, which describes where, how, and by whom they were treated, and 'Feeling a fraud', which explores why YP with MM feel different from other patients with cancer.

The term cancer does have a social stigma, as discussed earlier in this Chapter and generates intense feelings of fear and dread. Receiving an MM diagnosis, at least initially, appeared to be different. At the early stages, there was no real sense of foreboding as the physical symptoms were minimal as discussed earlier in the first theme. However, after the second or third reoccurrence of MM in the form of a lump, the YP and their family/significant other began to experience acute

feelings of fear and uncertainty. The timeline of these emotional reactions is quite different from that experienced by other cancer patients.

4.5.1 A Life Less Ordinary

For most of the participants, the disease had altered their life plans, and they required to try and adjust and cope with this. All the participants were forced to adjust in several ways. For Helen and Stuart, a young couple striving to build a life for themselves, coping with MM brought unexpected lifestyle and financial precariousness. Although Helen and Stuart are the only couple, there were recurring patterns and connections similar to some of the other participants within the study. Helen's mother had come from abroad to support and care for her daughter after the first surgery. However, as she could not speak English, her ability to support Helen at hospital appointments was severely limited, and Helen often had to attend on her own. Stuart's Italian family lived nearby but again were not fluent in English.

Helen, who had been unwell from her extensive surgery, required extended sick leave from her employment but without the benefit of any employer's sick pay. Stuart, her partner, had continued to work, but felt the pressure from one salary coming into the home. This was difficult for them both. Helen's mother provided some additional financial support, but this was infrequent, and Stuart's salary remained the only reliable income. Their experience of coping with such a steep decline in their financial position was a difficult adjustment for the young couple. There were two telling aspects of this theme. Firstly, adjusting to a change in life circumstances. Secondly, coping with and then living with the disease over an extended period. As Helen described below;

"Well, except for my mum and of course he (Stuart) paid for most of the things because for the last three months I didn't work. I spoke with a social worker and they said 'the least amount of time I can claim is six months' so I was off for just two and a half, I tried to do the same in March last year, but they said 'they don't want to accept your request because it is less than six months'. Even at work, I had

a good salary, and they move the salary to basically nothing because I cannot even pay for my part of the rent which is very stressful"
(Helen)

This financial insecurity resulted in them both being worried for their future, another source of stress, adding to the already hefty burden of daily life and living with skin cancer. Although Helen seemed to take the actual treatment experience in her stride, the time off work and not receiving sick pay was a real worry. Stuart did not mind working, but it was a physical and emotional challenge to work and then visit Helen when she was in the hospital for her surgery. This overall responsibility appeared to add additional strain to their relationship. Helen added:

"My doctor has just made me a feel in a good place, in a good way, it's been very clearly explained, everything that is going to happen, if you're feeling unwell what you have to do, so I'm kind of happy to see him so he can explain and because I will have to go by myself as you (Stuart) can't take 3 weeks off" (Helen).

Helen felt well-informed regards the further treatment she required and believed that this had been communicated well. She felt able to travel this new part of the journey on her own and to continue fighting the disease.

Patrick and his father, Terry, endured similar lifestyle and financial challenges to those faced by Helen and Stuart. Terry also faced financial insecurity from losing his full-time job but received state benefits, which helped support the family. Patrick's treatment, immunotherapy, made him so unwell that he had to spend considerable periods in hospital. Without this treatment, the MM would have likely taken his life. Terry was the primary carer for the family, which included Patrick's younger brother. Terry had to juggle these responsibilities carefully when Patrick was so gravely ill and struggled to stay with him when he was in the hospital. This disrupted the family as Terry opted to stay with Patrick for the duration of each treatment. During this time Patrick's younger brother was cared for by Terry's sister. Terry described the experience as difficult and trying to cope was particularly challenging at times:

“Probably, close to a mental breakdown right at the end, right enough. If anything, I struggled when we were given the good news, it was hard. Trying to cope with everything and not being able to sleep, I'd not been sleeping for like a month when he was in the hospital, just constantly, waking up and eventually, it calms you down” (Terry).

The narrative above highlights how emotionally and physically exhausted Terry was from caring for his son on a long-term basis. This had seriously impacted on the lives of the family and Terry was close to a mental breakdown. Without any apparent support, he had lost all hope and was struggling to cope with daily life as well as Patrick's treatment regime. Even when there was good news available about Patrick's disease, Terry was almost unable to process this due to his mental exhaustion. As Terry described:

“And then we were told 'oh, by the way, what we told you, there is no hope, well forget all about that', that was brilliant, but it was hard to kind of go from one and straight to another. So, we went from incurable was the word. Aye, we went from one extreme to what we went through to the next extreme a couple of weeks later and a phone call telling you everything's all right” (Terry).

This unexpected change in the forecast outcome brought a new challenge for Terry as he went through the extremes from 'a death' to an 'all right' situation. He experienced difficulties in accepting the new positive, good news about Patrick's disease and outlook. After preparing himself mentally over several weeks for Patrick's expected death, Terry had to quickly re-orientate himself to this new scenario and had to appear positive and happy for his son immediately. Internally, Terry was wrestling with his feelings and reaction to the change.

Another aspect of this theme was the inability of the family/significant other to adjust to the emotional demands of coping with the MM. This is best illustrated through John's narrative where he outlines how Eve struggled to retain a positive

outlook and was never able to escape the MM diagnosis and lived each day with the corrosive feelings of uncertainty gnawing at her. As John explained:

"I think even now to this day she struggles with it; I've been able to come to terms with what happened and talk openly about it, but for her, it's much more. I think it will always be because, for her, her son got cancer when he was 16, and that's not any mum's plan, all mums will have a sort of plan for their kids, but they will never tell the kids, and I think she thought at the time 'this is not what should be happening'. So, I quite quickly was able to think it through and think how am I going to move on from this thing, but I don't think she ever has been able to" (John)

John seemed to be able to rationalise this change in his future plans and prospects. However, for Eve, this disease had a profound effect on her. There was an utter sense of devastation of living through this and watching her child struggle to overcome the disease and then rebuild a life for himself. John recognised that Eve was riddled with guilt and had fallen into deep despair. John understood that this change in his mother might never alter, no matter how hard she tried.

4.5.2 The Treatment Experience

The treatment experienced by each young person and their families/significant other was the next step in this journey. Participants living with MM experienced a wide disparity in the range and type of hospital-based care and support. There is a widespread belief through evidence-based practice that the ideal treatment experience is delivered from specialist service centres that are age-appropriate. However, access to specialist centres was not readily available for all YP with this type of cancer, and distance was often problematic. This scarcity of specialist centres was evident through the narratives concerning the various treatment experiences, and these are illustrated below.

All the participants had various experiences to recall. Some were either treated within a surgical Ear Nose and Throat (ENT) ward for adults, an adult breast

cancer ward or a surgical adult ward. Only Patrick experienced his treatment through both children's and adult services. None of the other participants were treated in the TCT units, although two of the participants did receive psychosocial support from this charity.

Although John had waited six weeks for an urgent appointment to have the mole excised, he received a phone call within four days arranging for his admission to hospital. John was admitted to a specialist unit for women being treated for breast cancer. John and Eve had not known what to expect, but Eve did wonder why he received his treatment within a ward for women with breast cancer. John and his mother had initially expressed some disquiet around being treated in a female ward. However, the experience turned out to be positive in the most unexpected way, as Eve described:

"he ended up actually in the breast clinic, for his surgery, which in a way was lovely, in a way because it was all women, and all the nurses were fawning over him and looking after him because he was the only guy in there" (Eve).

For Eve, it was not about her son receiving care within a teenage environment. It was about the treatment and care he received. Although treated in a female ward for breast cancer, he was fussed over, and the nurses were very attentive to his care. At the time of admission, Eve had felt unable to accompany her son, so John's father had gone instead.

"His father went with him for that, because I was just a mess. By this point I was just like, I can't do this. And then, because he was brilliant, he was actually so strong, he never worried one bit, he said, about the whole thing. And, we would go for a walk and things, I would be like a zombie, and he would be wandering around trying to crack jokes and make me laugh, but I just couldn't get out of it. I was so, so, so worried. And then, so he had his surgery, and that was it all over. And they took quite a big excision, obviously at the time. So I kind of looked after him when he got home because he went into

spasm, his neck went into spasm and he couldn't, he was in agony, so I ended up having to massage his neck, and he suddenly went 'oh my God, it fine, it's fine'. But it was from lying like that for hours on the surgery table" (Eve).

Eve's experience was similar to the other family members/partner who described how well their child/partner had coped with the diagnosis and taking the next step towards the treatment. Nevertheless, Eve's worry continued, and there were days when she felt her life had no purpose. John and his father had adjusted to the need for surgery and were focused on dealing with the practical matters before and after. In contrast, Eve freely admitted to feeling "like a zombie" and felt she was failing to provide any meaningful support for John at this critical time.

Echoing his mother's comments, John described how his father accompanied him to the hospital as Eve was unable to do so. John's father had suffered from mental health issues for many years and Eve had taken on the role of breadwinner and acted as head of the family. However, in an apparent reversal of these traditional family roles, both mother and son came to rely on the father/husband, despite his struggle with everyday life. As John described:

"He doesn't work; he doesn't work at all. He suffers from mental health issues, so he's been not working for years now. Before I went into theatre, my dad accompanied me into a room to get all the wires and things attached, I'm assuming that it was a heart monitor, but I'm not really sure. I was scared; I had succumbed to genuine fear. I looked at my dad, and he held my hand. It was just nice to know that he was there, but we were helpless" (John).

Not having a full understanding of the procedures and treatments for MM can add to the burden of a negative experience, and this was evident in this family's case. John's father had gone with him as Eve had felt unable to do so. As described previously under the theme 'sense of guilt and helplessness,' Eve felt responsible for her son's disease. Going to the theatre to have the cancer removed was particularly frightening for John as no one had fully explained the procedure. His

father, on the other hand, was a great comfort, and it was reassuring to have the human touch and connection, which seemed to relieve some of John's fears and feelings of helplessness.

During the treatment experience, John and Eve had no contact with anyone facing a similar MM diagnosis and were unable to share their experiences. Both Eve and John were reassured by the fact that they received high-quality treatment and care. However, Eve commented that teenagers should be treated differently:

"I think there should be a designated area for teenagers, so they're not just shoved in with people having their breast removed or having plastic surgery done for whatever reason. I just don't think that was right, but, at the same time, it was what it was. Sitting waiting to be seen by the doctor in the Cancer Centre with all the adults was a bit, you know, 'God he is so young, so it made it worse almost, it was like all these older people with cancer, sitting there with. You know, I think you have to have the appropriate places, for an appropriate age" (Eve).

Eve believed that a dedicated unit for teenagers would have been a more suitable environment for her son. Being treated in an adult environment with older people did not seem right for her son. This experience of age-inappropriate environments was shared with some other participants who had no access to a specialist teenage unit. For those who did, for example, as a day patient, they found the specialist unit supportive, although there was no one else with MM being treated.

Patrick's treatment experience was different. He had received treatment at numerous adult and child centres, but healthcare professionals were undecided on the best place for Patrick's care to be delivered. Because he was 15 years of age when treated for his third MM reoccurrence, he was cared for in the adult Intensive Care Unit (ICU) as the treatment had made him very unwell. As Patrick remarked:

"When I first woke up, I looked around, and I was with older folk because I was in intensive care, and there weren't any kids in intensive care. And then I got moved into a sort of children's hospital, and I think I was the oldest in the ward" (Patrick).

This narrative describes how Patrick could sense where he was. It was not clear why he was in the adult ICU and not within an age-appropriate environment, and Patrick was quite confused by this. Patrick was aware that no 'kids' were present and when he did get moved, he was the oldest (at this time 15)

Terry suggested that there should be more consistency in the care for YP who fall between child and adult service age definitions. As Terry commented:

"He got caught between adult, yeah. If this (interviewer's research) is going to help anybody out, make sure that this never happens again. Because they are stuck between a rock and a hard place. There are maybe other kids his age, but they have to decide whether they are adult or child, one way or another, they shouldn't be passing them about" (Terry).

It was clear that there was confusion over where a 15-year-old boy should be treated. Patrick fell between the standard age definitions for each of the services involved in his treatment, and as such, there was confusion over where best to treat him and his family. There was no attempt to involve an experienced healthcare professional with the relevant knowledge and understanding of the specific requirements of Patrick's age group and his disease. This experience was important to Terry, not so much Patrick as he was too unwell at the time. As Terry described below:

"At the end of the day, he needed to be with doctors and nurses who care for kids and know about his cancer" (Terry).

Patrick was young and required to be cared for by knowledgeable healthcare professionals, experienced in caring for YP with MM. This was important to Terry,

even more so than the treatment environment, and he was adamant that Patrick should receive the 'best' possible care and treatment from specialist healthcare professionals who were educated in this disease and patient group, irrespective of the environment. This was evident for most of the YP, as George described:

"It's fine if you stay in X, you can hop on a bus and get to it, but for the likes of us they do have a local hospital, but they're useless. I mean utterly useless and to get to X takes over two hours" (George).

It was revealing to read George's experience of the local hospital and his lack of faith in the healthcare professionals who worked there. This was interesting as earlier in the Chapter, George and Richard had been suitably impressed by the local doctor who had acted without delay in removing the suspected mole. Like Terry and Patrick, and Helen, having to travel to the nearest PTC outweighed the risks of receiving care that was not appropriate for their disease or age group.

4.5.3 Feeling a Fraud

Malignant Melanoma is a cancer that in its preliminary stages offers no visible signs and symptoms to the casual observer; for example, the mole may be hidden. Other cancers such as Leukaemia can affect YP and bruising, paleness and lethargy being the most common signs and symptoms of the disease. For the participants, this generated a self-perception and associated feelings that they were different in some way from other cancer sufferers. 'Feeling a fraud' was a typical summation of the participants' experience as they compared themselves to other people, whether friends, family or acquaintances, who had suffered through other forms of cancer and the associated side effects. For those YP who experienced these feelings, they saw themselves as different from other patients with cancer and believed that they were deceiving people in some way about their illness and its severity and worried about what other people would think of them.

The mental anguish resulting from 'feeling a fraud' was very different from the 'guilt' some YP felt about having MM. This internal 'sense of guilt' stemmed from the profound impact their MM and treatment was having on their loved ones. The

young person could see the physical and mental toll the disease was taking on parents and life partners. Combined with the absence of any noticeable treatment side-effects, many of the YP in this study felt guilty for a long time. As a result, many of the YP lived in a constant state of anxiety.

Another telling aspect of the theme was that the participants' felt that they were treated in a distinct way and did not have the same support. The young participants discussed MM as being different, as seen below:

"You know you were saying about it being surgery, after that one it felt like I've had cancer but I've not had cancer and then this one, it feels like it's getting there, but I've not had chemo or radiotherapy, so it was like, I feel like a fraud, in some ways that, you know, when people think cancer they think chemo line (Central Venous Catheter) or whatever, in bed, looking like you think of like TV-type stuff, you know it's not really like that but it feels like you're saying you've had cancer, and 'I never thought I'd actually feel like this, but cancer guilt, survivors' guilt or whatever' - friends of friends have died and other people I have known with cancer" (Paul).

In the above narrative from Paul, there are two telling aspects; 'feeling different' and survivors' guilt.' Paul described feeling different from other people diagnosed with cancer. His individual experiences are drawn from friends and TV dramas and associated cancer being attached to someone who requires a Central Venous Catheter for the chemotherapy and other treatments. This is not the experience of MM; it is different from other cancers. The second telling aspect from the narrative is how Paul struggled with the death of a friend from cancer and the emotions around his mortality. Paul felt like a fraud and was guilty that his experience had been different and that he had survived his cancer when others he felt to be more deserving had not.

This was similar to what his mother Anna expressed:

"Actually, he said he felt a bit of a fraud because he had no illness whatsoever 'It just because he didn't have any pain or anything. I suppose he just felt lucky, not lucky to have cancer, but it can be operated on and not having to have the chemotherapy or the radiotherapy. Because my friend's daughter, who had Leukaemia, she'll have problems all her life and she probably never be able to have kids" (Anna).

Anna, Paul's mother, did not fully realise the seriousness of the MM. Previous personal experience, similar to Paul's, told her that Leukaemia was far more severe than Paul's MM diagnosis. Both believed that the MM was not as serious as Leukaemia and the treatment not as arduous as chemotherapy or radiotherapy. The side effects from these treatments endured by her friend's daughter had affected her thinking about cancer and its side effects. It is interesting to note that Anna could vividly recall the experience of her friend's daughter and still believed that Leukaemia was more serious than MM, even though her son was living through his third recurrence.

Paul described a boy from his school who had died from bowel cancer. In some strange way, it was as though he felt he was deceiving people who cared for him by telling them he had cancer. Paul explained below:

"He graduated with a first-class honours degree and then got bowel cancer. Don't know where else, liver, kidney, he died about three weeks afterwards. On paper, he was better than me at everything, but he died, and I survived, so it was for a while it was like, how does that work out?" (Paul)

In trying to make sense of his friend's untimely and unexpected death, Paul was confused, expressing feelings of low self-worth and asking why he survived, and others did not. Paul believed that his friend had achieved far more in his short life than he had. In his deliberations, Paul never once mentioned the 'lottery of life' concept but was trying to figure out why his friend had died, and he had not. This,

in a way, had confirmed in his mind that MM was not as serious as other cancers, and not as dangerous as his friend's bowel cancer.

The participants' experience of living with MM was consistently different from other patients with cancer, and this made them feel unusual and apart from the other patients. The feelings of being different grew from the perception that MM was treated in a distinct way from the outset of their MM journey. Some of the younger participants felt alone, but mostly, it was the families who felt isolated with no one to share their experiences. Families longed to be in a ward where there were others in a similar predicament to their child. Eve, John's mother, described this:

"I seemed to be the only one, at that time and I just wanted to speak to another parent that had had a child that had gone through it, exactly the same as me, I didn't want to go and talk to parents' who had had a child going through Leukaemia, because that was not the same for me" (Eve).

Eve is expressing how desperate, alone and isolated, she feels with no one to talk to. Her son seemed to be coping, but she felt the need to find support from others who were experiencing what she was going through. Having trained as a nurse, Eve was aware that patients with cancer, such as Leukaemia, have other families to talk with. Eve was asking 'why could this not be the same for MM?' It appeared that participants were treated separately, and therefore they felt different.

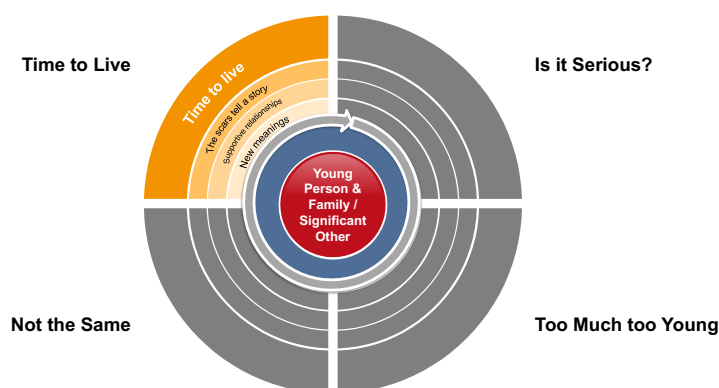
4.5.4 Summary

This super-ordinate theme, 'Not The Same,' revealed that living with an MM diagnosis changed their path in life and significantly altered their future life plan. Irrespective of the outcome, the MM diagnosis and associated treatment journey caused all the participants to re-evaluate their life and what was important to them. Nearly all the participants' confirmed that at some point, they all went through a period of self-reflection to try and cope with this disease.

A big part of the change to their life circumstances from MM came in unexpected ways. For many, the acute financial burden and associated worries meant that the fears around the MM treatment were compounded by the fear of financial uncertainty and loss. For many, the financial impact alone could change their lives beyond recognition.

The treatment experience was unique for each participant for many reasons. Not one participant was treated within an age-appropriate unit, and consequently, some felt that the healthcare system was not designed to meet their particular requirements. However, it was evident that they often felt isolated and alone and that their care was not seamless, apart from the CNS (not always a TYA CNS, but, a Skin Cancer CNS), who offered support. There was also the casual TCT psychosocial input for some who were treated as a day patient. In particular, there was no support available for the families/significant other. Due to the public's widespread perception of conventional cancer treatments, patients with MM who presented with no initial symptoms or treatment side effects reported that they felt different from other patients with cancer. Besides, having had personal experience of knowing someone who had died from cancer added to this perception and the feelings of being different. This emotional response was based on the different treatment protocols for MM, different services and the lack of support services in distinct locations.

4.6 Time to Live



The super-ordinate theme, 'Time to Live,' represents the final part of the MM journey. It was important for the YP to remain positive about the next part of their MM and

life journey. It seemed they had adopted a range of emotional coping strategies early in the journey and had accepted the need to live with their cancer diagnosis. This positive thinking allowed them to redefine their goals and focus on the

meaningful aspects of their lives. For the family/significant other, this was described as “we’ll all just beat it again” (Terry) alongside the uncertain futures and having to live with MM through recurrent times.

This final theme was categorised into three sub-themes. Firstly, ‘The scars tell a story,’ which refers to the YPs physical and emotional scarring as a consequence of having MM and being ‘marked’ by the disease. Secondly, ‘Supportive relationships’ which outlines the importance of support from family and friends and the interconnection of these relationships. Finally, ‘New meanings’ which revealed the importance of being positive and moving forward with their lives alongside an uncertain future. Although for some, especially the parents, there were days when fear and worry would consume them. Fear that the cancer would return meant continually checking their child’s skin for any sign of abnormal moles.

4.6.1 The Scars Tell a Story

Physical and emotional scarring was present for all the YP in this research. Severe physical scarring, had ‘marked’ them and was present for all, with most of the scarring visible around the head and neck area, upper leg, groin, abdomen and arms and told the story of their cancer journey. Some scars could be hidden or disguised, while others could not. This hiding seemed important for some, but on the whole, did not appear to affect them. Several YP reported that members of the public were inquisitive about their scarring while others felt that they were entitled to make uninvited comments and remarks about the physical scarring. As George explained:

"Some days it's like I've been in a bar fight with Chuck Norris. I was at a breakdown with my job, a couple of weeks ago, and I was sitting in the van, and a boy saw my scar and went 'oh, what happened there?' and I said to him I had cancer and he goes 'oh, Melanoma cancer?' I was like 'aye', and I said 'have you had it?' He says 'no, I know folk that have'. So that's the first time I've ever heard anybody speak about it. So, it's not well known, whereas I think it should be" (George).

George felt defined by his scarring and although pretended to his father that the physical scarring did not bother him he was consciously aware that it was extensive. He was going about his daily life when questioned for the first time about his physical scarring. George was surprised that the young boy knew about melanoma and was astonished as no one else had ever commented or questioned George. It seemed that George's surprise was genuine, and he was pleased that, at last, someone else had encountered MM and understood what it was.

Richard, his father, described how his son preferred to keep the scarring covered. He had a different perspective on the physical scarring from George and believed that his son deliberately kept it covered and 'hidden.'

"If he takes his beanie off, then you'll see it then, he says it doesn't bother him, but he has that hat on all the time" (Richard).

Richard explained that his son never removed his hat in order to keep the scarring hidden. George concealed his scarring to keep it hidden from the fear of people asking difficult or awkward questions. Richard believed his son George wore his beanie hat all the time as he was self-conscious of the scars the surgery had left.

The other male participants faced similar issues. Paul described his physical scarring as though he had been physically attacked:

"I don't really think that the scarring bothered me that much. I've got scarring all over my neck and back, so if my hair is short, you can see scarring on my neck. It's two things, the acne, you feel people judge you for that because they think 'oh you're unclean' I went out to a barbeque with my mum shortly after I had the staples removed and it was like someone had hit me with an axe. But I don't really think it has affected me. If anything, it's the acne that's done that" (Paul).

Paul was trying to convey that the scarring had not affected him but simultaneously expressed very clearly how traumatic it was for him by comparing the scarring to

a physical injury resulting from an attack. This experience has commonality with Richard and the tensions the scarring brought to their lives.

The physical scarring seemed to be just as arduous as the emotional scarring. This was the constant reminder of the cancer when they looked in a mirror or when people commented felt the need to comment or ask questions. The physical scarring would always be a part of them, as John described below:

" For me, the days with cancer will never end, and I will always be attached to it in some way, or another. I don't think I'll ever accept that it happened." (John).

John was a young man with a fearless and dauntless character, but similar to the other YP, he was affected by the physical scarring. Being 'attached to it' was evidence that they had experienced and survived this type of cancer, as it was always there. The evidence was visible to all and would be present for the remainder of their life, however long or short. This scarring, and what it represents, would be part of his normal daily life and John had accepted that his life was now different from before the MM diagnosis.

"I think at first, just being young, I thought I can't have a scar on my neck, people are going to stare at me and think who is this big scary guy. Mum was laughing because I think of it, a bit like my tattoo, and it's a good talking point if anyone asks me about my scar" (John).

It was suggested that the physical scarring had become part of his identity and sense of self, which is similar to the other YPs experiences of their scarring. They were conscious of having this had altered their body image, important to them, when young. The physical scars, in particular, were focal points for conversation as the YP were aware that their physical body had changed, altered by the scarring from the disease.

On top of the scarring from the MM, Paul was still traumatised from his earlier acne scarring, as discussed earlier in this Chapter. The combination of the MM

and acne scarring had a profound psychological impact on Paul, and also it was visible on his neck. He felt that strangers judged him as not caring for his skin correctly.

"I wanted home but (because of) the cut and the clips (part of the surgery) I just was in a lot of pain. I had to sit up to go to bed, which was painful, I was out of breath constantly, so it was horrible, horrible at night. Then, of course, depression came back that night. But the worst part was the drain and getting the drain removed, that went, it was that length, and it was all the way up around the back of me. They were pulling it out, the pressure hadn't come off completely, so they were fairly yanking it." (Paul).

Post-surgery, the impact for all YP was immense, and this was the first time in the MM journey they felt 'unwell' and in discomfort from the surgery. The emotional scarring was evident as they recalled their experiences of after being in the hospital and being left to suffer from their post-surgery wounds. Paul was discharged early from the hospital, as he wanted to be at home. He was suffering physically and emotionally, both of which worsened at night when his mother was asleep, and he was alone with his thoughts. The post-surgery period appeared to be the agonising part of the MM journey as Paul described so vividly. Months after this, his discomfort, 'emotional scarring' was apparent, which was a similar experience for other YP and the family/significant other who were trying to support them.

For Helen, her experiences of physical scarring were minimal, in direct contrast to the experiences of other participants. For Helen it was likely that the physical and emotional scars run deeper than would first appear, given the comments about changes to her lifestyle. Both were concerned with moving on with their lives, as Helen expressed blow:

"When I see all my scars, I don't see them as a big problem, I maybe can't wear a bikini anymore, but it's fine. I can't even go to the beach yet" (Helen).

Helen realises that her body had changed, and she knows the consequences of having endured many surgical procedures to remove the cancer. Previously it was 'normal' for Helen to go to the beach as she comes from a small seaside town in southern Europe where the beach is where she went most weekends with her family.

For Stuart however each time going to see the Doctor brought emotional turmoil and fear. In his mind, each visit seemed to bring more bad news;

"We're going to see him tomorrow to find out the results of the scan, which I hope, is ok" (Stuart).

4.6.2 Supportive Relationships

Cancer is a disease that affects the whole family/significant other as well as friends. The role of families/significant other is important within the MM journey, often more so than friends, due to the relatively young age and immaturity of some of the participants. Family/significant other were asked for advice, guidance and emotional support. This role was often difficult for the family/significant other as they grappled with their fears and worries for their child/loved one. Being 'at hand' for positive, optimistic and cheerful advice was a challenge for many of the families/significant other despite all recognising the importance of trying to hold the family/partnership together. The retention of the family unit provided everyone with support and reassurance through the solace they found in laughter, shared experiences and in-depth discussions about the disease.

"I take each day as it comes, as long as he's here and he's hearty and as long as he's happy. Then we'll just soldier on. When he'd been told he had cancer at that time, I said look, he sat down beside me, I said 'it doesn't matter, whatever happens, I will be with you every step of the way,' and that's the way it is to be. I go with him to all appointments. As a parent, that's one of my roles in life to see him through these times" (Richard).

Richard always accompanied his son, even though he was 23 years of age, to every appointment. Richard was taking control and caring for George as best he could based on his firm belief that this was his role as a father. Describing the journey as “we’ll just soldier” on suggests fighting another battle, should it arrive. No matter what, Richard would be there for him. Richard was trying to be realistic and provide his son with comfort and security. This narrative shows the interconnection between father and son and that they were experiencing the journey together.

"My dad comes with me; I am able to go myself, but as the hospital is a bit away, he comes with me for the drive. He has always been there for me (George).

The importance of supportive relationships is clear and extremely important within the MM journey:

"We've all worked really hard together, to pull each other up, I suppose. So yeah, to pull each other out of everything and sort of support each other I suppose. And it's been really supportive, it actually brought us closer, the whole experience, I suppose, we've all said that as a family it brought us closer than we could ever be. And more, we're so grateful to have each other, if you know what I mean" (Eve).

MM was not only affecting John; it was also impacting on his family, emphasising the interconnection rather than the ‘individual’, and they were all suffering in their way. It was all-consuming. The family were close before the MM journey began, but now, they were even closer than before with each member of the family supporting the others. They craved support and reassurance, especially when the days were at their darkest and they were plagued with worry and fear. It was the intensity of this support that made the MM journey bearable.

Supportive peer-to-peer relationships with friends was an essential consideration for some of the YP. Some friendships would prove to be durable throughout the MM journey, but others would wither away under the relentless emotional pressure of the disease, with the enforced absences diluting existing relationships. For George, his family and friends were vitally important:

"Apart from the family, my friends were there for me as well. So, they held tight, after my second operation, I was still in bandages and everything, my friend picked me up we went to a car show. So, it's not like I was stuck in the house or anything. They were there helping me as well, through the whole thing. My mum and dad have also been there through the whole thing" (George).

George described how fortunate he was to have such good friends. They had seen him through the good and the tough times, throughout his MM journey. His friends had been reliable and had stuck with him throughout. George's friends were reliable and supportive, along with his family, and this was evident in all parts of his life. Their support kept him moving through his MM journey. They were his strength.

For John, the journey was bearable with having such strong friendships throughout;

"They were great... they are such a good bunch, and that was another huge thing of my cancer, as soon as I'd been diagnosed we were meant to be going on a trip with school, so, I had to text them and I said 'look guys, you got to come round to mine tonight because I've got to have a chat with you all' So they all came round, and I told them on the night I had been diagnosed and I broke into tears, because that was the thing as soon as I tried to tell someone, it was like that's real now. So I told them and just about straight away, we just about started making jokes, and that was a big thing, I think being able to laugh, I was able to sort of make it this sort of small thing instead of being like 'wow, this is cancer'. I was able to take a

step back and think 'look, just think about this rationally and don't overthink it'. So that was the big thing for me, I found laughter and being able to joke quite therapeutic. Because I felt myself, I didn't feel like I was pinned to having cancer” (John).

John, although on the surface phlegmatic for most of his MM journey, also expressed how fortunate he was to have such good friends, with close personal relationships having been built over several years. John found it difficult to tell his friends about the cancer initially, but once broached, the discussion brought a cathartic emotional release. It helped that the friends could laugh with John and distract each other from the seriousness of the disease. The shared sense of humour, often very dark, brought strength to John and helped him feel 'normal' again. John had found himself as a person again, not defined by the cancer. This was different from his laid-back attitude, as described earlier in the Chapter.

John, however, was aware of how the disease had impacted on his mother, Eve. This experience had taken its toll on her and John was acutely aware of this:

“My mum was there throughout, and I think my journey with cancer, well I quickly came to terms with it and didn't really think about the magnitude of what was going on until watching other people. Like my mum, we have always been close, and with my family and to watch them not know what was going on inside of me was probably the scariest thing. It was never really like, oh no I got cancer, this is really bad on me, it was more like this is not good for anyone around me” (John).

In this context, John has a strong connection to his family but mainly his mother. This disease has had an enormous effect on the whole family. John could accept having the cancer, but it was difficult to observe how this had impacted on his family and those close to him rather than himself. They had all embarked on this journey together.

For Patrick, in sharp contrast to John's experience, prolonged absences from school and associated social events disrupted existing friendships, and they would never to return to 'normal' again. As Patrick expressed his feelings of social isolation:

"Dad's always had to take care of me and pals don't like me just now because I have cancer and they feel sorry for me. That's not a pal" (Patrick).

Patrick's comments above reveal the deep state of his social isolation from his immediate peer group and the emotional disruption associated with this. He was also describing the most important relationship with his father, where his trust was implicit and never falters. Patrick relies on him for everything. The social stigma and possible fear of cancer had changed Patrick's friendships in a negative way which was not common to all YP in this study. Some friends wanted to pity Patrick and make a point of supporting the 'cancer victim.' Other friends have been driven away by the fear that cancer was contagious, and they did not want to be associated with the "pal" with the disease.

4.6.3 New Meanings

Malignant Melanoma impacted on the daily and future lives of all the participants. Many expressed having developed a more profound sense of meaning in their lives that derived from the experience of dealing with MM. By the end of the MM journey, many felt a strong motivation to embrace life and all its opportunities and reported an increase in their confidence and strengthened relationships with family, friends and loved ones. This, however, was not a universal experience for all participants as some continued to worry about the cancer returning.

Helen, who has found her deep levels of resilience through dealing with profound adversity such as a third relapse and unexpected financial stress, commented:

"OK, I'm going to die. I never thought this. We always tried to be positive, I think this is why I am normal when speaking about my

story. I will never be able to go back to my normal. I am not feeling fully healed, still in some pain, but I just feel I need to restart my normal life.” (Helen).

Helen was determined and positive right from the outset of her MM journey, which was in tandem with some of the families' stories, as discussed earlier in the Chapter. Despite the seriousness of her cancer, Helen refused to be 'beaten' and did not let the cancer destroy her life or life she was trying to build with Stuart. She was fully aware that her health will never return to the pre-cancer days but was determined to restart her life. Helen and Stuart's life before the MM had disappeared and they now had other more important parts of their life to consider. It did appear that Stuart worried about the future, perhaps without Helen, as he now knows the gravity of Helen's MM. Helen wants to restart her life where Stuart was pausing which illustrates the uncertainties.

"We will not get married yet. First of all, it's more the money situation, because obviously, we don't have a lot of money, I mean she's (Helen) not been working for a long time this year, and she still has to have more treatment, we will know about this soon and she will need to be there on her own" (Stuart).

Helen and Stuart plan to marry once the treatment has finished, and they can continue with their life. Helen and Stuart, similar to Terry, have had to face financial precariousness. Prolonged absences from work or periods of unemployment have led them to experience financial difficulties which in turn had affected their lives. Helen and Stuart's life was interrupted, but they also had to live with the constant fear and worry about the cancer recurring. The MM had affected their life plans significantly, and at some points, it seemed as if their future life together was hanging in the balance.

Most of the participants had found some positive meaning in their lives. Even though four out of the five YP who were interviewed had a recurrence of the disease, they all stayed positive. Yet, it was for some of the parents who found this hard. As Eve, John's mother describes below;

"Because it was a different cancer. But I think cancer is just cancer, you know. I still think sometimes, I still worry about him all the time. I mean, I check his moles every month. I am the 'mole mapper' of the whole family. I've become more anxious because of it. I've changed, I know I've changed" (Eve).

For Eve, the term cancer was serious, no matter the specifics of the disease. Since diagnosis, Eve's self-imposed role was now to be the mole checker and mapper for the whole family, a role she has taken very seriously. The MM experience has changed Eve, which was parallel to the experiences of other family members and loved ones. Eve described how anxious she had become because the MM had afflicted her child. Although wanting to move on for the health and benefit of her family, Eve remains trapped in the mole checking cycle and was continually checking for early indicative signs of MM in other members of the family.

Although on a new path, with new meanings for most, there was still the worry and fear that the MM could return at any point in their life. The YP knew they would be required to continually monitor their skin for any signs of the disease returning. The daily routine of checking the condition of existing moles, and looking for new ones, would need to continue for the rest of their lives. Terry explained:

"He is just so worried, he is going to always have to check, it's as simple as that, and he does check every day in the shower, and I keep an eye, but if or when the bad times come, if anything happens again, we'll all just beat it again as simple as that (Terry).

Many of the YP had to adjust their daily routine in response to the MM. For some, this was a practical change to their lifestyles. Fear, anxiety and worry over the possible reoccurrence of MM was the main driver for this change in behaviour. For many, this change was seen as a positive, proactive step in protecting their future health and well-being. Paul seemed to be coping well with this new regime in his life:

“Well, I’m content. I don’t think I’ve been happy for a very long time. Well happy, happy. I not sad or anything anymore, really, but I’m content. I’m happy with where I am and just not outwardly” (Paul).

Paul’s feelings of contentment sprung from his acceptance that the worst was behind him and that his life could move forward, but he would remain vigilant in looking for signs of the MM returning. This is something that would stay with him and was present in all the participants with the notable exception of one mother, Eve, John’s mother, who was stuck. Eve would worry for the rest of her life and found it difficult to move on.

“it will always be on my mind, it will still always be there, thinking it could come back, and hopefully they’ll keep on top of checking. He’ll check himself obviously” (Eve).

No matter what journey this disease had taken them on, the YP, for the most part, were optimistic and could see a future for themselves. Most had plans for the future, and like Patrick, would be positive while looking ahead and considering the future:

“I will be 17 in August, so I’ll be starting my driving lessons and going to college” (Patrick).

Patrick had turned 17 and had been on the journey of living with MM since he was 11 years of age. He was optimistic and excited about learning to drive, and when accomplished in his driving would have transport back and forth to college. At the college he would receive an education, the education he had missed out on from being unwell with his MM.

4.6.4 Summary

The 'Time to Live' super-ordinate theme described how all the participants' journey with MM had brought new and different meanings to their lives and forged a different path for them. In moving forward, they had not been defeated by the

disease. All continued to make plans for the future, despite the uncertainty and interruption to their lives that the MM diagnosis had delivered.

The YP's scars, both physical and emotional, were a constant reminder that they had experienced and successfully endured all the trials that the MM had presented to them. These scars now represented a key part of their present and future identity, and most of the YP had come to terms with this.

Supportive relationships were critical to the YP's MM journey. They all viewed their MM experience as a shared journey with family/significant other and friends. As most of the YP lived at home with their family/partner, it was their parents/loved one who became their primary carer, supporter, adviser, advocate and friend along this journey. In addition to the immediate family member others were also affected, for example, the siblings. This disease had impacted significantly on all their lives in many different ways, although there were shared experiences for most of the journey.

The participants were mainly positive and optimistic, with a newfound meaning to their lives. The worry of reoccurrence would remain as an almost permanent presence in the lives of some YP and their family/significant other, but they were still able to move forward with their lives.

4.7 Conclusion

This Chapter has documented that living with MM was an emotional journey for all the participants who described their lives as being interrupted. The data suggested that being diagnosed with MM was a significant life event and, in some circumstances, can trigger emotional responses that compel the individual to find new and additional meaning. Also evident was that living with MM was a family disease and support was required for both the YP and the family/ significant other.

The core 'Life Interrupted' conceptual thread is introduced in Chapter 5 to capture the fluid and interactive nature of the processes and experiences of living with MM. Further discussion follows to illustrate the unique journey for YP and their

family/significant other living with MM and the dynamic and multifaceted interrelationships that exist.

Chapter 5: Discussion and Conclusions

5.1 Introduction

This Chapter presents the research aim and questions. It then discusses the core conceptual thread, the ‘Life Interrupted’ metanarrative, which illustrates the thematic structure and interconnections between the YP and their family/significant other in living with MM. A fundamental part of the MM journey for all hinges around the unique and often complex factors that interplay between the YP and their family/significant other and I present a conceptual representation of this journey. This maps the sequential stages in their MM journey, the multifaceted and dynamic relational interplay between the YP and their family/significant during the journey alongside the individual and shared experiences of living with MM. The main findings embedded within the four superordinate themes are then critically discussed and evaluated, exploring the meaning, importance and relevance of my research to theory and practice. Finally, I present my overall conclusions.

At the time of writing, this study was unique in exploring the experiences of YP, in the 16 to 26 years age bracket, and their family/significant other living with MM. The earlier narrative reviews in Chapter 2 identified that there was no current qualitative literature exploring the experiences of YP and their families/significant other living with MM. During the 1970s MM in YP was rare (Bader et al., 1985; McNally et al., 2014), but over the intervening decades, there has been a marked increase in the reported incidence of MM in YP around the world. According to the ISD (2019), the most common diagnoses reported in YP across Scotland were carcinomas (21%), lymphomas (18%); and melanomas and skin cancers (16%).

Research into YP with cancer has focused on the more common forms of cancers, such as Leukaemia and Hodgkin’s (Taylor et al., 2018; Fern et al., 2013b; Zebrack et al., 2014). These studies have recognised shortcomings and were discussed in my second literature review in Chapter 2. Specifically, I identified that the methodological approaches used were not always appropriate to provide an in-depth analysis of the YP experiences alongside the family/significant other. Additionally, the focus in previous literature has been on all cancers rather than

one specific disease and has been on the individual young person to the exclusion of the family/significant other. In concluding this Chapter, I discuss my study's original contributions to the broader body of knowledge, the strengths and limitations of the research, before highlighting and summarising my recommendations for future research, practice and policy. Finally, I present my overall conclusions from this research.

5.2 Research Aim and Questions

At this point, it is relevant to re-state the research aim and questions in Table 5.1 and confirm that these have been answered through the IPA approach and associated research methods. It was clear that each young person and the family/significant other had established dynamic interconnections built around pre-existing inter-relationships. My research findings in Chapter 4, have been presented to reflect the nuances of these dynamic connections and relationships. Consequently, the research questions were addressed through the four superordinate themes and the key discussion points critically analysed and synthesised within the available cancer literature that included MM in other age brackets and seminal work specific to this patient group.

Table 5.1: Research Aim and Questions

Research Aim and Questions	
Explore the experiences of YP and their family / significant other living with MM within Scotland.	
1.	What are the experiences of YP and family / significant other living with a malignant melanoma?
2.	What are YP and family / significant other experiences of the support and care they require or need?
3.	What further support or improvements in care do YP and family / significant other identify?

Through a rigorous IPA based analysis of MM in the 16 to 26 age group and their family/significant other, this section is grounded in the data gathered during this research and is contextualised within existing theoretical understandings. It is also important to acknowledge that the experience of cancer takes the form of a

trajectory or 'journey'. This involved a series of events along the way, including recurrence for some. In my study, four out of five YP experienced a recurrence as part of their journey, and these were explored within the narratives recounted in Chapter 4. Willig (2011) explains that through her own experience of living with cancer, individual understanding changes as patients move along their cancer trajectory and each point on the journey involves a shift in their epistemological stance towards the disease.

5.3 The Metanarrative – Life Interrupted

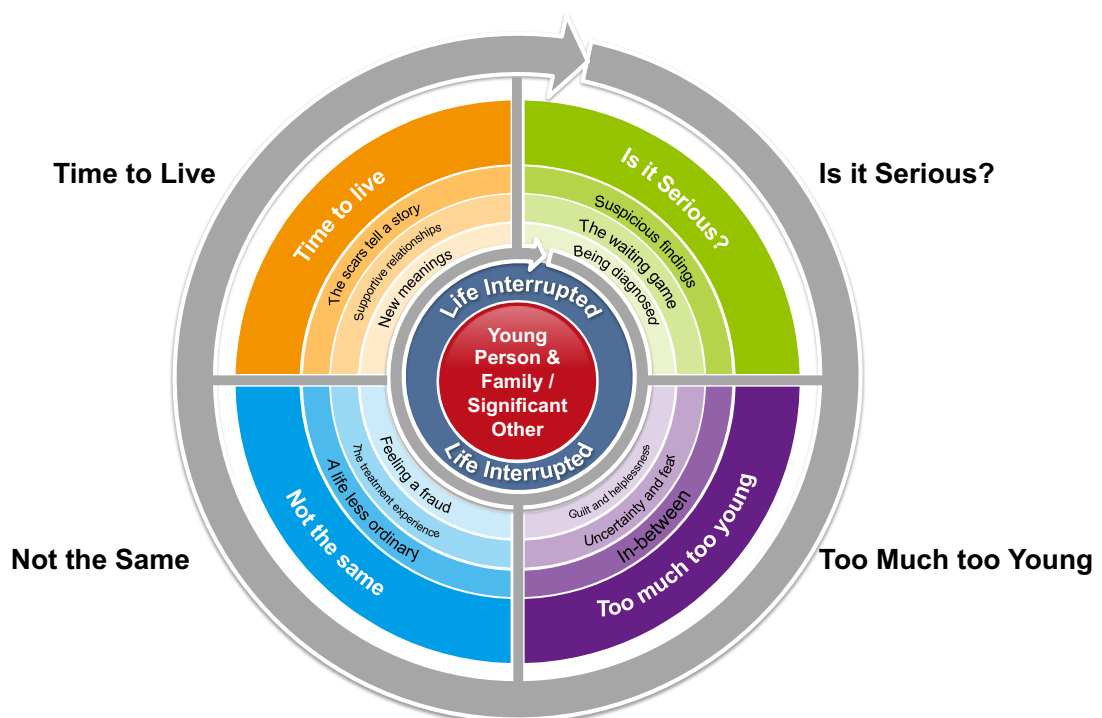
The metanarrative of a 'Life Interrupted' represents the interconnections and inter-relationships between the identified super-ordinate and sub-themes and acts as the core conceptual thread throughout the findings. This study also captured the uniqueness of the multiple voices as opposed to the individual voice (Larkin et al., 2019), which is a novel addition to the IPA approach. Multiperspectival IPA retains a commitment to idiography in data collection and analysis but broadens this by combining two or more focal perspectives, allowing for the relational and intersubjective to be captured. This was a critical finding within my study, where the multiple voices contributed to the overall MM experience. The concept of a metanarrative is that recurring hermeneutic (meaning constructing) practices constitute a familiar 'lifeworld' (Wilson, 2018). From this perspective 'Life Interrupted' is an appropriate metanarrative in respect of which more particular themes in my research are situated (Eatough & Shaw, 2019; Carel, 2016; Smith et al., 2009).

Throughout my study, I have endeavoured to capture the 'connectedness of meaning' established during the hermeneutical exploration of the experiences of living with MM while integrating the findings into this overarching metanarrative (Eatough & Shaw, 2019; Gilstrap, 2007; Osborn & Smith, 2006; Somers, 1994, p619). The 'Life Interrupted' metanarrative was evident in the experience of every participant living with MM, irrespective of the patient and family background, circumstances or outcome. The data collected from this study was organised hierarchically into themes, and following the iterative process of analysis, the 'Life Interrupted' metanarrative was identified from the participant's lives. 'Life

interrupted' speaks to the various ways that participant's lives were interrupted due to the cancer diagnosis, and the journey this disease took them on as well as the unsettling emotions that were experienced during this journey.

Based on my findings, a thematic structure of the 'Life Interrupted' metanarrative is shown in Figure 5.1 to illustrate the core conceptual thread and the interconnection between YP and the family/significant other. The interconnection between the four super-ordinate and the 12 sub-themes is also shown. Some participants repeated parts of the journey for a second or third time, due to recurrence of the disease. The central concern of IPA is with the individual lived experience, which we understand to be a form of "concernful involvement" (Yancher, 2015, p109) which considered the shared experiences that were present throughout the entire journey. Concernful involvement allows for the disclosure of truth about aspects of the world, but truth, from this perspective, must be understood as unfolding, multifaceted, and inexhaustible. Events, objects, places and people within the world matter to the individual and in order to make sense of the lived experience the researcher required personal reflection in order to reach an understanding as was discussed in Chapter 3.

Figure 5.1: Life Interrupted – A Thematic Structure



Interpretative Phenomenology Analysis (IPA) is 'underwritten' by hermeneutic philosophy or fundamental informing and from a hermeneutic perspective, a 'characteristic of the lifeworld' (Eatough & Shaw, 2019) or where the participants recurring events occur. The metanarrative provides an overarching interpretation of the participants' experiences of living with MM and is concerned with describing the whole story, specifically one which integrates to the other narratives. In living with MM, YP and their family/significant other experienced interruptions and setbacks to their customarily familiar or anticipated lifeworld's (Eatough & Shaw, 2019). Eatough & Shaw (2019) offer an understanding of the lived experience of a particular person with Parkinson's disease. Through an IPA case study approach, they recognised that the experience is indivisibly woven into the person's lifeworld. Lifeworld describes how each of us inhabits a subjective situated world and one in which we share "ever-present characteristics" within the situated worlds of others (Eatough & Shaw, 2019, p51; Smith, 2019). This was evident throughout the participant's experience in my study, where the participants were all experiencing the same disease, which brought about similar emotional and physical changes.

Virginia Eatough writes: "IPA seeks to retain the rich and personal detail of the particular while pointing to ways in which the particular illuminates (and is illuminated by) characteristics of the lifeworld that are common to us all. These lifeworld features provide a useful lens through which to examine the concrete particulars of an individual situation and say something about its more universal features" (Eatough & Shaw, 2019, p51). The phenomenon of lifeworld or 'lived world' is situated within the accounts of other people who are also sharing the same experience, such as the family/significant other (Larkin et al., 2019). By lifeworld Eatough & Smith (2006) discuss the world in which we experience, that is filled with meaning, attempting to capture what matters within an individual life (Smith, 2019; Wilson, 2018).

During the YPs' lives, the MM experience arrived at a time when they were in the process of developing their early adult life plans and were at a fundamental crossroad in their lives. Despite the varying individual personalities and personal circumstances, my in-depth research acknowledged that these participants were

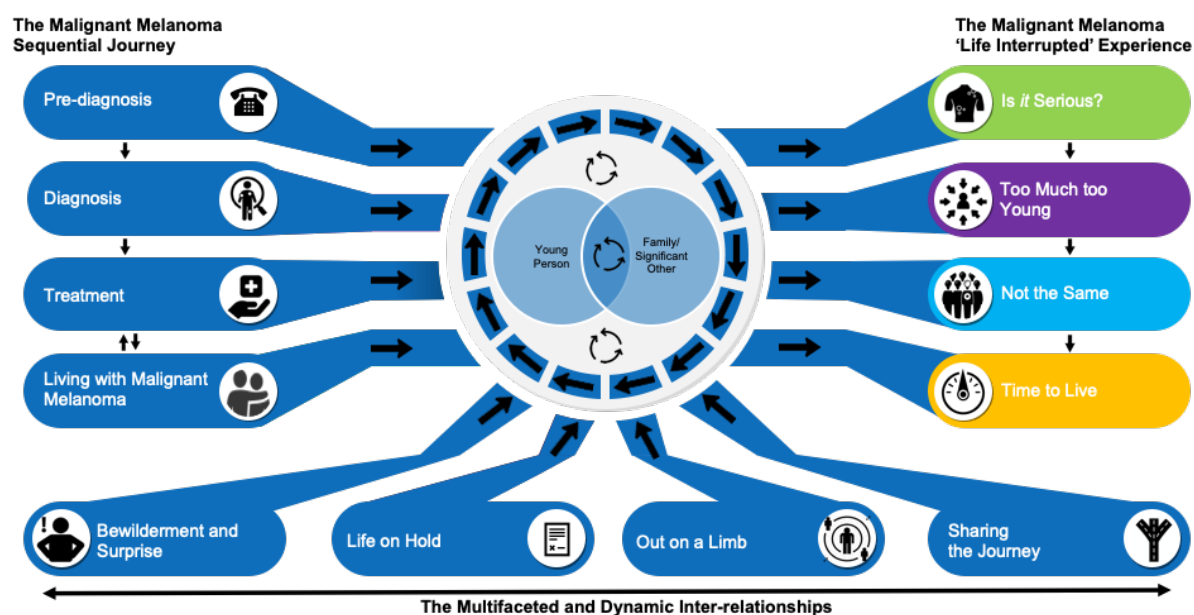
experiencing a significant interruption to their typical 'day-to-day' routine and plans. School and career plans along with life and prospects for adulthood were affected by the disease and its treatment. Prolonged periods of hospitalisation for this disease were rare, for most, and many YP at the beginning of their journey did not recognise that they were unwell or living with cancer, unlike other forms of cancer affecting YP. The family/significant other also felt that their lives had changed, with their hopes and dreams for their child's future altered by the disease.

5.4 Living with Malignant Melanoma – The Journey

Although the MM journey can be similar in some respects to other recorded cancer experiences, such as the conceptual model proposed by Taylor et al. (2013), in my study the MM journey varied for each participant, but they shared a similar experience which was different from other forms of cancer in YP. In particular, the impact of MM can only be fully understood when viewed through the prism of the dynamic and complex family/significant other relationships. The ebb and flow of these intense relationships can, in some situations, magnify the impact of the physical disease, with the emotional turmoil often rivalling the physical manifestation of the disease. Equally, different relationships may help the YP and the family/significant other cope with the disease in a more positive and supportive way. The importance of these unique and changing relationships in living with MM should not be underestimated.

To capture the unique and complex factors at play in the MM journey for each young person and the family/significant other, Figure 5.2 illustrates three core interlocking parts of the journey that was revealed through this research: (1) the sequential stages of the MM journey from pre-diagnosis to living with MM; (2) the multifaceted and dynamic inter-relationships between the young person and their family/significant other that sit at the core of the journey; and (3) the individual and shared physical, emotional and social experience of 'Life Interrupted'.

Figure 5.2: The Malignant Melanoma Journey – A Conceptual Representation



Part 1 charts “the MM sequential journey” and illustrates the typical cancer trajectory for most YP living with cancer with vertical arrows showing the flow between each stage. For some, the journey also involved a return to treatment when a recurrence was experienced. Horizontal arrows from each stage of this journey, intersecting with the core of the diagram, reveal that each individual step was taken in tandem with the family/significant other and was influenced by the existing complex and dynamic family/significant other interpersonal relationships. This meant that each young person experienced a unique journey in terms of the manifestation of the physical disease and its emotional and social impact.

Part 2 centres the complex and dynamic family/significant other relationships throughout each MM journey. It was these emotional and social interrelationships and interconnections that provided the resilience to cope with the true impact of the disease and shaped the ways that lives were interrupted as the MM journey progressed.

Part 3 captures the experience of having life interrupted illustrated in the four super-ordinate themes revealed by this study: ‘Is it Serious’, ‘Too Much too Young’, ‘Not the Same’ and ‘Time to Live’.

The complexity of these multifaceted interrelationships and interconnections between the YP and their family/significant other are encapsulated in four shared responses shown at the bottom of the diagram. These shared feelings and experiences are dynamic, ebbing and flowing, intensifying and receding, as the MM journey progresses, yet each played a vital part in the overall lived experience. Presentation of the core threads and themes of the thesis in this visual way helps to conceptualisation “what lies between” (Larkin et al., 2019) and shows how the experiences YP and their family/significant other were inseparable.

The following critical analysis and synthesis discusses the profound life impact an MM diagnosis, and the subsequent treatment experience can have on the young person and their family/significant other at a significant period of their lives. The core conceptual thread alongside each of the four superordinate themes and findings are now discussed in more detail.

5.4.1 Is *it* Serious?

For YP and their family/significant other participating in this study, the MM journey commonly started with encountering unexpected physical changes in the condition of their skin or pre-existing mole. There was a general lack of awareness of this disease and most did not associate melanoma as being cancerous. Personal awareness of cancer, in general, was from their own experiences of a friend or a relative who had lived or died with other cancers, such as Leukaemia or Bowel Cancer, but for most, there was limited specific knowledge, understanding or awareness of skin cancer. This lack of awareness, and wondering whether it was serious or not, impacted later on in their journey in living with this disease. Apart from Helen, who had lived all her life in the ‘sun’ and had grown up protecting her skin, and Eve, who was an adult nurse, had some knowledge of skin cancer. None of the other YP or family/significant other had any awareness of melanoma. This bewilderment and lack of awareness were present from the beginning of their MM journey.

Apart from these physical changes, there were often no other symptoms which are different from other common cancers in YP. These changes, when noticed,

promoted action to visit their GP or health professional to investigate and diagnose their suspicions. For many, the time of diagnosis involved new environments, unfamiliar language, unsatisfactory communication and inadequate healthcare processes. Treatment protocols for MM are stage-dependent and typically delivered through outpatient appointments at non-specialist cancer treatment centres, and hospitalisation is usually for surgical procedures only. Malignant Melanoma is not a disease that is often associated with children and YP, and generally is un-noticeable to the general population and indeed often to themselves (Ferrari et al., 2019; McNally et al., 2014). As was evident within my findings, the changing moles were often 'hidden' or unnoticed by YP and their family/significant other. This was a challenge for some. In addition, they did not experience any abnormal symptoms from the mole site, apart from Helen. Whether it was 'out of sight out of mind', the participants tried not to worry and to carry on as 'normal'. For one participant, Helen, it was the discomfort and bleeding which prompted her to act. Each individual young person and family/significant other described in great detail the events that led them to seek medical advice.

Often changes to the mole can be perceived as trivial and not signifying possible skin cancer (Bird et al., 2015; Kyle et al., 2012; Walter et al., 2010). Ensuring that the YP and the healthcare professionals have an awareness and are knowledgeable about melanoma, would support a positive life experience in living with this disease. Changes to the mole, being identified earlier, would present a more favourable outcome for the YP and their family/significant other preventing unnecessary worry and fear (Kyle et al., 2012; Hajdarevic et al., 2014; Walter et al., 2010). Epidemiological research has found that early diagnosis of melanoma prevents the disease from infiltrating into the lymph system and other organs of the human body (Ferrari et al., 2019) and preventing the spread of the disease.

As highlighted above, the experience of finding the mole, being bewildered and surprised was a common reaction amongst all the YP and their family/significant other. Apart from Patrick, all the other participant's abnormal mole was detected by the YP themselves or through daily life routine. Research by Smith et al., (2007) reported that YP may attribute physical signs and symptoms of other types of cancer to more usual problems such as stress and injuries. It was also suggested

that YP have an inbuilt sense of immortality combined with a lack of self-awareness and a belief that cancer would never happen to them (Smith et al., 2007; Gibson et al., 2013; Pearce, 2009). Similarly, the YP in my study shared these feelings, and this added to their initial bewilderment and surprise in finding the suspicious mole.

The challenges associated with early recognition of MM and seeking prompt, professional advice within the YP population needs careful consideration and should not be underestimated within the actual cancer trajectory. Several studies have shown the importance of education around the signs and symptoms of cancer and emphasise the importance of seeking appropriate medical guidance and support without delay (Albritton & Bleyer, 2003; Kyle et al., 2014; Smith et al., 2007). In my study, YP, the family/significant other were also experiencing similar feelings of surprise, tinged with a degree of suspicion – ‘was this serious or not,’ and denying that this disease could be affecting their child/loved one. As seen in Figure 5.2, this is the first step for many in the MM journey.

The emotional bewilderment associated with the changes to the mole was never static, and worry began to erupt as they progressed through the journey to diagnosis. The difficulties participants described were documented throughout Chapter 4 and the first super-ordinate theme. Although the young participants reported that they did not feel unwell, unlike many other patients with cancer who experience many unwanted symptoms, they did begin to worry about what they had found. Waiting for an appointment, and the results of the biopsy were emotionally draining for many and contributed to the strain of wanting to be believed and their symptoms accepted. However, as they progressed to the diagnosis, early signs and symptoms of changes to their mole were not always fully recognised or accepted by the GP.

Being fully aware and able to recognise the signs and symptoms of cancer is, however, an essential factor for YP and has been investigated further within recent studies (Hajdarevic et al., 2014; Hubbard et al., 2018; Kyle et al., 2014; Meyer, Christensen, Tolstrup, Dalum & Køster, 2019; Rouhani et al., 2009; Walter et al., 2010). According to these studies, skin cancer awareness in this age group is

extremely low, and self-awareness, knowledge and understanding are critical to early diagnosis and preventing the disease from spreading and increasing the threat to their future lives.

Although all the participants acted on the changes to the mole, without delay, none of the YP and their family/significant other had knowledge and understanding of skin cancer, apart from Helen and Eve as discussed earlier in the Chapter. Most of the participants reported within their narratives the lack of awareness about the dangers and risks of melanoma and the fact that there was no available information within the healthcare centres, compared to other cancers such as lung cancer and smoking. A cross-sectional study by Kyle et al. (2014) undertaken in Scotland, with 2,173 adolescent secondary school pupils, highlighted the influential role awareness and education play in understanding skin cancer, the risks associated with UV exposure and encouraging safe sun-protective practices. Similarly, Horsley, Charlton & Waterman (2002) carried out a study in England where school pupils' aged between 10 and 16 years were included in a survey questionnaire regarding their behaviour in the sun, opinions and experiences of sunburn. Horsley et al. (2002) found that the young participants believed that having a 'tan' made them beautiful and therefore exposed themselves to the sun whenever they could. They found that education was needed to challenge the notion that a 'tan is beautiful' and proposed using social teaching methods to empower pupils to carry out sun protection in real life. However, as reported within their narratives, sun-related behaviours or tanning were not typical for most of the YP in my study.

Much of the literature found on MM focuses on the epidemiology and sun-related behaviours or tanning (Hubbard et al., 2018; Murray & Turner, 2004; Tripp et al., 2016; McInally, 2018). The evidence suggests that MM could be entirely avoidable by heeding the warnings about exposure to UV light, irrespective of its source (Murray & Turner, 2004). Murray & Turner (2004), through a mixed methodology study, found that more self-awareness was required around the risks of overexposure to the sun or sunbeds. This study gathered information from people aged between 18 to 32 years living in Merseyside and through an IPA approach that having a tan made them feel better about themselves and was essential for

their body image. However, for many, this behaviour became addictive, similar in many ways to the social pressures experienced around smoking and alcohol consumption in some parts of society (WHO, 2019). Early awareness and the associated changes in behaviour and attitudes have the potential to reduce the burden of melanoma in adolescence and early adulthood, as well as in later life through the establishment of self-awareness and for some other protective health-related behaviours (Kyle et al., 2014). Most of the YP, from what they could recall, had not participated in any form of unprotected sun or UV light exposure or sought to have a tan, which contrasts with the Murray & Turner (2004) study. The families also reported that they had always tried to protect their child's skin from overexposure to the sun.

Nevertheless, most followed up on their suspicions with either their GP or dermatology clinic. As discussed earlier in this Chapter, this is unusual in this patient group as most YP can be ambivalent about illness, but it may have been that alerting their family/significant other to their findings prompted them to seek medical attention, without delay. Congruent with a small number of qualitative studies, it is common for YP to postpone seeking medical attention after they have had specific or non-specific symptoms (Gibson et al., 2013; Fern et al., 2013b; Miedema et al., 2006), and most keep these 'worries' hidden from their family/significant other.

The majority of the participants in my study reported that their GP initially dismissed the concerns. Reflecting on their experiences, many described the false sense of security they received from the GP at the initial consultation. However, continuing symptoms meant that despite these initial reassurances, they found themselves going 'back and forth' to consult with their GP multiple times. Their worries and concerns were only taken seriously once the mole had been eventually biopsied or excised. Time spent waiting for a diagnosis ranged from one to 10 weeks, depending on where the participants were located. This part of the MM journey was reliant on the time taken from primary excision of the mole to the histopathology results being relayed to the healthcare professional and further action taken. This waiting time allowed the participants the opportunity to research their disease through the internet and fuelled the belief that the delay in diagnosis

may have allowed the disease to spread within their bodies. This experience added to the stress already being felt by the participants.

Although the incidence of melanoma is rising in the YP population globally, it is still relatively rare for an individual GP to experience a young person with cancer such as MM (Miedema et al., 2006; Scottish Government, 2019a). A study by TCT (2015) found that close to a third (29%) of young patients with cancer were only diagnosed when their health deteriorated to the point of admission to an Emergency Department (ED). Nearly a third of young patients (32%) had a poor diagnosis experience indicated by three or more visits to a GP before referral. Almost a quarter (24%) had been to a GP with symptoms but attended ED when symptoms worsened. Melanoma can be difficult for the GP to diagnose, but patients should be referred to appropriate specialist services if the lesions are suspicious (Marsden et al., 2010; Melanoma UK, 2019; Scottish Government, 2019a; TCT, 2015). Early detection, clearly defined referral pathways and equitable access to specialist services, minimises unnecessary delays and enables treatment to start as promptly as possible (Murray & Edgar, 2012).

Government policy in the UK stipulates that patients, including YP, with suspected malignant skin lesions, should be seen by a specialist who has knowledge and experience of this disease (Marsden et al., 2010; Macbeth, Newton-Bishop, O'Connell & Hawkins, 2015; NICE, 2005; 2015). In addition to this, CYP in Scotland who present three or more times with symptoms that do not appear to be resolving, or following an expected pattern, should be considered for referral for a second opinion regarding the concerns (Scottish Government, 2019a). The difficulties of supporting YP with this disease also extends to where the journey begins, how the diagnosis is made and communicated to the YP and their family/significant other.

For many, the journey started with an undiagnosed, and often minor, skin complaint that had transformed into a life-changing and threatening condition once the word 'cancer' was mentioned. Despite seeking medical attention for their suspicions about the mole, the participants were not prepared for the diagnosis. The sudden onset of the disease was not expected, and it was alarming that it had

occurred at this critical stage in their life. Healthcare professionals relayed this diagnosis as 'melanoma' and only when prompted by the YP or family/significant other did they confirm the diagnosis as 'skin cancer'. This first part of the journey was an emotionally fraught and challenging experience, although it was not always clear whether some of the YP and the family/significant other had taken '*it*' as seriously as other types of cancers. Young people, in particular, referred to the 'cancer' as '*it*', opting to avoid naming the cancer as a way of detaching themselves from the MM, which may have served as an effective coping strategy for some.

Most of the YP had limited knowledge about melanoma, but as discussed in the previous section, they did have experience and knowledge of other cancers. This illustrated how vitally important appropriate and compassionate communication was from the healthcare professionals when delivering such news to YP with or without their family/significant other in attendance. There is a rich seam of literature around communication for YP with cancer, but this does not always include the family/significant other (Fern et al., 2013b; Gibson et al., 2013; Grinyer, 2009). The literature also reports on the accuracy of the information they receive (Lea et al., 2018; Mulhall, Kelly & Pearce, 2004) and whether this is helpful or not.

Many of the participants felt as though they had not been provided with sufficient information during the diagnosis. Additionally, the environment in which the news was delivered did not make them feel at ease. Openness, honesty, transparency and communication are the essential key skills that all healthcare professionals should possess to ensure that YP and family/significant others have enough support when the diagnosis is relayed (Al Omari & Wynaden, 2014; Hølge-Hazelton & Olsen, 2018; NMC, 2018). This was an essential part of the MM journey and one that was missing for all the participants in my research. Apart from the information and support given from the CNS, which was inconsistent, there was no information or support available.

Provision of accurate and timely information would have supported and assisted the participants in understanding the diagnosis, which would have helped them understand and comprehend what lay ahead. Most YP requested involvement in their care and treatment, although they also indicated that they wanted their

family/significant other to be present alongside them. Consequently, participants sought out this information for themselves, using the internet as a go-to, easily accessible and convenient resource. The information sourced from the internet inevitably added to their worry and concern as they had no one to support, interpret and filter the information in the correct way. Information around statistics, survival rates and the probability of spread throughout the body all intensified their worries and fears. Often, this information was not shared as they attempted to protect one another from the harsh reality of what may lie ahead. One mother, Eve, described how she had contacted the Melanoma Support Scotland charity, out of desperation, but did not find this useful as there were no YP or families in a similar situation to discuss their experiences.

Lea et al. (2018) discussed the importance of online resources for YP with cancer. This study interviewed 21 young people, aged 13 to 24 years based in England and sought to determine and understand how YP with a cancer diagnosis use the internet to source information and support their needs. The internet is a fully integrated part of our everyday lives, and online resources must be developed to maximize the potential support available. However, caution is advised in the use of these resources as the participants in my study discovered more about MM than they had initially wanted or needed. Having a professional to explain these findings was expressed by my participants as imperative to prevent unnecessary worry and confusion.

There are a few studies in the adult population that concern MM and healthcare delay (Gajda & Kaminska-Winciorek, 2014; Hajdarevic et al., 2014; Walter et al., 2010). The Hajdarevic et al. (2014) study was carried out in Sweden with 71 patients aged between 18 to 80 years of age. This study sought to describe patients diagnosed with MM depending on their initial medical contact, MM stage, sex and age between initial diagnosis through to treatment. Sweden has a similar population and statistical profile to that of Scotland, and again, the incidence of MM is rising each year. This study found that one reason for delayed diagnosis was related to a lack of medical attention for suspected change in the condition of existing moles. Although the participants in this research were older, the findings are similar to the YP in my study, where inaction on the part of the GP was evident.

Miedema et al. (2006) support these findings and suggest that delay was a cause for distress in young adults with suspected skin cancer. There is some limited literature around YP with cancer in general which considered the impact and consequences of delay in diagnosis (Gibson et al., 2013). It cannot be ignored that in many cases, a significant cause of the delay results from the inaction of the YP themselves or the medical professional (Miedema et al., 2006). This was not seen in any of the participants in my study apart from one young male, Paul, who waited (two weeks) until a routine dermatology appointment for his acne before mentioning the change to his mole. However, there was a significant delay from the GP for some of the participants and Miedema et al. (2006) highlight how the inaction of both parties could exacerbate the MM.

Gajda & Kaminska-Winciorek (2014) literature review suggests that the GP needs to be aware of how to detect suspected melanoma and how to use a dermoscopy (examination of the skin using a microscope) for the screening of skin cancer. The inability to recognise early changes can have severe implications for patients and is detrimental to future lives (Ali et al., 2013). This cannot be proven empirically from my study but was a significant concern for the families/significant other, especially as four out of five of the YP were diagnosed with stage 2 or 3 and subsequently went on to have recurrence. Most reflected on this waiting and the GP to take them seriously as a negative experience and one that could have been avoided. Delays in diagnosis can cause distress and unnecessary worry, and for this disease, in particular, early recognition is vital to prevent metastasis (infiltrated disease to the lymph system and organs) (Ali et al., 2013).

In summary, the YP and the family/significant other had minimal experience of melanoma prior to diagnosis. They did not see this disease as serious and it was not a cancer that they associated with themselves or their child/loved one. Being self-aware, having knowledge and an understanding of melanoma was fundamental to the process and sequential journey. Unique to this study was the family/significant other who were a vital part of the journey and one that was shared. Most experienced a false sense of security in their GP but identified that obtaining an early diagnosis was crucial, especially from the healthcare professional. Consideration of how this was communicated, and associated

information provided also needs to be reviewed as part of improving the overall experience for YP and their family/significant other living with MM.

5.4.2 Too Much too Young

Being young and receiving an MM diagnosis, at a transitional life stage on the threshold of young adulthood, did impact on their life trajectories. All the YP, apart from Helen, lived at home with their family. All had experience of being in the hospital for a short period, apart from Helen and Patrick. Most had experienced a recurrence apart from John, and all were at University or in employment apart from Patrick. The young participants were undergoing many forms of developmental transitions such as developing from a child to a teenager or teenager to young adult and being conscious of their sense of identity and increasing independence, autonomy and responsibility. The young people were at a stage where their lives were filled with life-affirming potential. The critical role of these emotional transitions in dealing with the MM diagnosis and its impact was illustrated in Figure 5.2 under 'Life on hold'. Young people's developmental pathway was interrupted in different and lasting ways; however, the YP did not want this disease to define them.

Young people with cancer face unexpected life-changing and extraordinary challenges to accept, manage and overcome their diagnosis during these transformative years of their lives (Grinyer, 2007; Soanes & Gibson, 2018; Woodgate, 2006; Zebrack et al., 2014). Similar to my findings, through a grounded theory approach, the theory of establishing and protecting an adult identity suggests that YP may interpret cancer as an interruption to their life events (Soanes & Gibson, 2018). This study was one of the few that included one young participant with MM in the 19 to 24 age bracket and established that interrupted biography was resumed through re-establishing their sense of identity by focusing on internal and external support resources. In addition, Bury's (1982) work focused on the person living with a chronic or long-term illness such as cancer. His work draws attention to the way illness interrupts the expectations and plans that individuals hold for the future, requiring "a fundamental rethinking of the person's biography and self-concept" (Bury, 1982, p169). He further suggests that living

with a chronic illness, for some people, does not necessarily amount to a fundamental and profound biographical disruption but can be experienced as biographical continuity and normality. Bury (1982) and Soanes & Gibson (2018) highlight that being diagnosed with a chronic illness, such as cancer, often leads to loss of self and identity as YP struggle to keep their independence and hopes for their futures alive. Although most of the YP did not regard MM as 'chronic' or indeed that they were unwell, they did experience altered life plans but managed to continue with their lives. All of the YP participating in my study were adamant that they did not want their lives to be defined by the MM as it was generally seen as a "mere bump in the road".

Within my study, Bury's theory can be related to some of the YP, for example, Patrick who appeared to have experienced an altered biography, mainly during spells of hospitalisation or being unwell from the treatment. Similarly, John and Paul experienced this altered biography, especially when while preparing themselves for their futures. My research findings suggest a critical, more profound impact on the young person resulting from an interrupted biography at a crucial transitional moment in their life trajectory. Another experienced interruption was where YP reported the loss of friends, school and the life they had known before their MM. This altered sense of their lives was also present for the family/significant other.

The theory of loss and their sense of self was seen in most of the YP as they struggled to find a new way of being within their lifeworld (Charmaz, 1983). Both Bury (1982) and Charmaz (1983) discuss loss and uncertainty that arrive with a chronic illness and how people adjust to this within their new lifeworld. However, although most of the participants expressed this sense of loss, they all reported how they progressed with their lives, albeit on a different path. The core conceptual thread once again aligns itself to this interruption as opposed to disruption.

Being young and having cancer challenged the YPs' life trajectory at this crucial stage in their lives when feelings of loss of control and gaining autonomy are pivotal to normal growth and development. Coyne, Holmström, & Söderbäck

(2018) discussed these concepts and referred to situations where YP refrain from being the sole decision-maker and actively seek the participation of their family. However, recent literature has advocated empowering YP to make their own decisions where and when possible, but this should be negotiated between the YP and their family/significant other (Davies et al., 2015). Davies et al. (2015) discussed the limited evidence available regarding YP being involved in decision making about their cancer treatment. This study suggested that this involvement was crucial, and there can be several tensions between YP and family members which stem from paternalistic approaches to care. Yet these paternalistic approaches can be viewed as being in the best interests of their child or young person. Within my study, the YP were happy to include their family/significant other and found this support beneficial to their overall experience of living with MM. It was not always easy for YP to make these decisions on their own, especially when they were still living at home. Cancer is inherently a family disease, impacting on each individual and all facets of the young person's lifeworld and that of the family/significant other. At the time of diagnosis, and throughout their MM journey, support from their family/significant other was crucial to each young person as illustrated in Figure 5.2 earlier in the Chapter.

Family-centred care (FCC) has for many years been the pillar of children and young people's nursing in the UK and some parts of Europe (Franck & Callery, 2004; Nethercott, 1993; Smith & Coleman, 2010, Whyte, 1997), and person-centred care (PCC) within adult nursing practice (Coyne et al., 2018). My study would suggest that both FCC and PCC are important concepts and present themselves within different parts of the MM journey. The majority of the YP in my study made the decisions together as a family/couple, aside from Patrick where his father, Terry, who had withheld the truth when initially diagnosed at the age of 11 years, to protect his son. This approach to the care delivery may have been influenced by the fact that four of the YP lived at home with their family, while Helen was living independently with her partner. Research suggests that YP with cancer need autonomy and support, yet they also require protection and their family/significant other to support them through the cancer journey (Kelly & Gibson, 2008; Hokkanen et al., 2004; Kyngäs et al., 2001; Davies, Hannigan & Kelly 2019).

During the adolescent years, YP are moving from dependence to independence, sexually maturing and developing their own identity and their view on the world with themselves in it (Grinyer, 2009; Soanes & Gibson, 2018). It is well documented in the literature that during this stage of growth and development, YP tend to present with an increased self-consciousness and sense of self, and when family and peer relationships can be complicated. This is also a period where, as Erikson (1972) proposed, identity formation is the critical developmental task of adolescence. Young people need to form their own identity at this stage and is a significant step towards gaining self-confidence in order to stride forward and take control of their own lives. Being diagnosed with cancer can add to this complicated and challenging stage of their lives, as was seen in my study and discussed earlier in Chapter 1. Biography is not an objective, detached record of life. Instead, it is the life as constructed by the person in the present (Soanes & Gibson, 2018). It was particularly pertinent for Patrick, for example, to emphasise the continuity of himself between the present and the past. In doing so, he was helping to preserve his sense of self against the impact of the disease. It was important for all the YP not to be identified solely by the disease, however, because of the extensive scarring, some were unable to separate themselves from the disease.

Living with an MM diagnosis reinforced the YP's dependencies on their family/significant other just as they were attempting to assert some independence from the family unit. This dependence on support from the family/significant other extended across a range of different life situations. As discussed in earlier Chapters, the YP during this period were trying to be independent and assert themselves within the world before the MM arrived. Healthcare professionals require to work with both the YP and their family/significant other to ensure the needs of the whole family are met adequately.

Woven into my research findings was an underlying sense of 'uncertainty and fear about their future' which was a sub-theme of 'Too Much too Young' as seen in Chapter 4. Uncertainty is not static or restricted to a single event that occurs in one's lifetime. According to an Australian study by Levy et al. (2018), uncertainty shifts along a trajectory according to how people deal with their diagnosis, the

information they receive, and how they respond to treatment. For many of the young participants in my study, their disease was progressive, and therefore they had varying experiences of uncertainty, which erupted at different intervals along their journey. This also had a profound impact on the family/significant other. However, for most of the time, they had the necessary treatment and continued with their lives, which is different from other forms of cancer within this population.

In Chapter 4, I presented data which suggested that the participants' experience of uncertainty and fear were subjective and a socially constructed experience which was often uncomfortable and led individuals to develop coping strategies to minimise this uncertainty. For the participants, having known people who had endured cancer and subsequently died added to their emotional state of being. Their journey seemed to resonate with the unknown, the uncertainty and fear of dying from the disease, like other patients with cancer, had become a possibility. At this point, the awareness, fear and worry became almost tangible as each tried to comprehend what the future might hold. Earlier plans and ambitions had to be rearranged and postponed, replaced with the immediate priority of dealing with the emotional, social and physical impact of the disease. When seeking guidance, advice and support to see them through this challenging time, many participants reported a significant lack of support from the healthcare system. The notable exception to this was the references to the value provided by the CNS role, where available. However, the CNS was not always a specialist within YP or skin cancer. Ongoing support, in terms of emotional, informational and practical, would have been welcomed by all throughout the MM journey.

Although most of the participants were not faced with the possibility of death at the time of being interviewed, in reality, they had considered this possible outcome. For example, Patrick and Terry were initially given 'bad' news about the expected outcome only for the specialist to retract this prognosis weeks later. Searching for solid ground was evident in the form of hope and striving to understand what lay ahead through balancing hope and despair. Participants could recall relatives and friends who had died from cancer, and until searching the internet, they had no real association with MM and the possibility of death. Power, Bell, Kyle & Andrews (2019) focused on a collection of empirical papers

from social and health geographers that explored the way people seek to sustain a sense of health and well-being despite a myriad of challenges associated with life. This paper explored these challenges often around the non-linear way of how people seek to find ways of living with ill health and trying to adapt to new ways of being that can allow them to move through their lives, often with hope and expectation for their futures. Power et al. (2019) considered many dichotomies to gain an understanding of adversity which could then be applied to the participants in my study who had defined their lives before MM by planning their future lives. All of the participants in my study adapted to this adversity by finding meaning and purpose, mainly through carrying on with their lives and regarding the MM as an interruption. For most support from family/significant other and friends helped them find the strength and ability to move forward and remain hopeful.

The YP and the family/significant other wanted the opportunity to discuss the disease and to share their experiences with others. This was recognised as an essential source of support and an effective coping strategy. The challenges of coping with the disease were magnified along the journey for each participant, especially for those who had to deal with a recurrence. A study by Juvakka & Kylma (2009) who interviewed six YP aged 16 to 21 years in Finland found that there were two dimensions to how YP coped with cancer. The study highlighted YP having hope, intentional hope and inner hope, which was similar to the Power et al. (2019) paper that sought to explore hopeful adaptation strategies to cope with adversity as discussed above. All participants in my research were able to find hope, internally and externally, from coping strategies that included family/significant other and friends. The Juvakka & Kylma (2009) research on inner hope found that YPs religious beliefs allowed them the strength to cope which was similar to research carried out by Al Omari et al. (2017) and Al Omari & Wynaden (2014). Both these studies used IPA to explore coping strategies for YP in Jordan. The findings from Al Omari et al. (2017) were similar to Juvakka & Kylma (2009) in that the participants, all Muslim, had strong religious beliefs and believed that Allah would protect them. It is interesting to note that in my research that none of the participants mentioned their religious belief, but all discussed other coping strategies to support them along their journey, which mainly included the belief that they would get better. The greatest coping strategy was from not having to

face this MM journey alone; they all needed support from their family/significant other and their friends. This interconnection and inter-relationship highlighted the uniqueness of this study and how the MM disease had impacted on the whole family/relationship and people who were important to the young person.

Research from Engvall et al. (2011) described the value of adopting emotional coping strategies such as hope, positive thinking and seeking support from others. Alongside the family/significant other support came from the CNS. Knowledge and information provided by the CNS gave the YP and their family/significant other the strength and confidence to consider the practicalities of living with MM and how to move forward with their lives. In addition, there was support available from TCT, but this was not consistent for all. In adopting these coping strategies, most of the participants were able to reach a level of acceptance regarding their life with MM, past, present and future allowing them to redefine their goals and focus on meaningful aspects of their lives. Emotional and social support were absent from their journey apart from when some of the participants met with the CNS. This experience, however, was not common across all the participants, and some felt isolated and alone. The Hughes, Williams & Shaw (2017) literature review suggests that YP require psychological support during their cancer trajectory to deal with the issue of personal mortality. The family/significant other also required support yet there is very little research around this need. A recent study by Kenten et al. (2018) sought to understand the experiences of YP with cancer for whom a cure was unlikely. This study, carried out in England, included young adults aged 16 to 40 years, of which four had melanoma. However, the age of the YP with melanoma is not made clear. Through a multi-method realist evaluation, this study found that current care towards the end of life was challenging when curative treatment options had been exhausted for the YP. This had severe consequences for the families and the healthcare professionals involved in the care delivery. This study has some similarities to my research, with appropriate support for YP and their family was identified as missing from the journey.

Participants wrestled with the uncertainty and fear, sometimes unspoken, that the disease would end their life before maturity. For those who had endured an earlier episode of MM and now faced a second or third recurrence, the uncertainty and

fear intensified and added more turmoil to their lives. Although the YP had MM, they did not express that they were in any pain from the disease but did discuss the resulting discomfort from the surgery. The sub-theme 'A sense of guilt and helplessness', illustrated how guilty some YP felt for having caused this interruption to the family unit and for having this disease. The family/significant other were also feeling guilty and blamed themselves wondered why this had happened to their child/loved one. Guilt was well described in the narratives from most of the participants, with many YP feeling guilty about having a form of cancer, that to them was not as severe as other cancers. The family, especially the mothers, felt guilty that their child had to endure this disease and blamed themselves. Listening to the participants reconstruct meaning and coherence about their journey was a crucial part of the caring and healing for all participants and one in which they shared as part of their interview. Despite the growing recognition of the distinct needs of YP with cancer, studies on the subjective experiences of cancer in young adulthood still indicate that there are unmet needs. These include particular sensitive issues such as living with serious life-limiting conditions and the fear of death or loss of life (Grinyer, 2007, 2009; Kim, White & Patterson, 2016).

Many of the YP and their families/significant other were fearful about death and mortality but found it difficult to discuss. Many had previous experience of family/friends who had not survived cancer, which added to their guilt and helplessness. Although most of the participants believed that MM was not as serious as other cancers, the thought of death still loomed, especially when experiencing a recurrence as this meant that the disease had spread within their bodies.

To conclude, the confirmation of the MM diagnosis brought an overwhelming sense of the unknown into all the participants' lives, especially the YP who were looking forward to their life plans and ambitions. During the journey of living with MM, they often felt alone and isolated with no other young person or family/significant other in the same situation. This impacted on how they recalibrated and restructured their existing lives and future plans. Emotional and social support was mostly absent, but they had support from their family/significant

other and for some, their friends. Within this part of the journey, the emotional and social impact on the YP and the family/significant other was profound. Young people felt guilty that they were well but had to deal with the social stigma that is attached to cancer. In addition to the natural worry for their welfare of their child, many family members felt guilty and blamed themselves for the disease even though they reported that they had not exposed their child to the sun.

Following both an FCC and PCC approach was essential as the YP fluctuated between independence and dependence.

5.4.3 Not the Same

Fundamentally, the majority of the participants in my study felt they were not like other participants living with other forms of cancer and therefore felt different, alone and isolated. 'A life less ordinary', a sub-theme of the third superordinate theme, captured the challenges of adjusting and coping with their new lives including changes to their physical well-being, financial worries, changing relationships and an altered future. For some, the acute financial burden and associated worries meant that the fears around the MM treatment were compounded by the fear of financial uncertainty and loss. Within my study, there were a few participants for whom financial worry was a recurring concern. Terry, Patrick's father, had been made redundant, and he struggled financially as he was the sole provider for his family and could not work while caring for his son. Helen was too unwell to work and received no sick pay from her employer. This financial worry was a burden and affected day-to-day life decisions and added further stress to their relationships.

As patients with melanoma are diagnosed through a different route and do not always see the specialist in cancer care until much later in their journey (CRUK, 2019b), this may have contributed to their overall perception of having no specialist support. Accessing specialist support, similar to other YP and their families with other types of cancer, may have helped ease their feelings of not being the same as others with cancer and feeling alone without any support. However, the participants all reported that the care received was to a high standard and within a safe environment, albeit not specialist care or age appropriate.

Participants also expressed their concerns that they were not supported or cared for in the same way as others they had known with a different type of cancer. This experience left the YP and their family/significant other feeling as though they were 'Out on a Limb' which is illustrated in Figure 5.2 and not part of the same journey as others living with cancer. The treatment and care were not specific to the YPs' age nor their cancer, although there were links with the specialist cancer services for those experiencing a second or third recurrence and required systemic treatment. Feelings of being different from other patients with cancer were common in all the young participants and for some of the families, which in turn brought about the feeling of being a fraud.

The majority of the participants in my study had not spoken to other YP or families/significant other with MM. This support was something they longed for. They all spoke about this lack of support and not being with others who were experiencing the same disease. This would have eased their burden and feelings of not being the same as other YP with cancer or being different. Although most acknowledged the support from the CNS, as indicated previously, and contact was mostly through the outpatient clinic appointments. Research by Lea et al. (2018) supported the use of online groups as a support mechanism and concluded that they would be a useful addition to YP and their family/significant other living with cancer.

The feeling of being different was expressed in the participant narratives and was connected to their lives with MM and the treatment experience. This feeling was reinforced by the participant's personal experience of seeing others cope with a cancer diagnosis. These findings were similar to those identified in a study by Bird et al. (2015) who explored patient experiences and the supportive needs of adults with MM, the youngest being 31 to the oldest aged 70 years. Through a grounded theory approach Bird et al. (2015) found that patients living with melanoma saw the disease as being different from other cancers and resulted in feelings of isolation with no one to share the heavy burden. This study also found that significant support from healthcare professionals was required to help ease their fears and worries.

In terms of service provision, YP with cancer were once depicted as the “lost tribe” (Michelagnoli, Prichard & Phillips, 2003, p2571) and “on the margins of medical care” (Whelan, 2003, p2573). Although most of the YP in my study were not treated within a TYA specialist unit, most were satisfied with their hospital care and being with older adults. Apart from Patrick, none of the YP wanted to be within a children’s ward, and although some of the family members did mention that the care environment was inappropriate, a children’s ward was not discussed as an alternative.

There is increasing recognition in the UK for healthcare for YP to be different from the approaches in place for children and adults (Lea et al., 2018). Approximately 2,400 YP aged 15 to 24 years are diagnosed with a malignancy each year in the UK (CRUK, 2019) and cancer is the leading cause of death from disease amongst this age group (O’Hara et al., 2015). Being diagnosed with cancer, such as melanoma, generally has a worse prognosis when compared to children or older adults (O’Hara et al., 2015; Stark et al., 2015). As discussed in Chapter 1, the *Cancer Plan for Children and Young People in Scotland* aimed to ensure that CYP aged between 0 to 25 years diagnosed with cancer have equal access to the best possible care and treatment as early as possible (Scottish Government, 2016; McNally & Willis, 2017). As expressed in my study, a number of the participants felt that they or their child were ‘In-between’, not a child and not yet an adult. Some of the YP in my study were hovering between childhood and adulthood, while others were considered as a young adult. Yet, all apart from one were still relying on their family to provide guidance and support across a range of life situations and choices.

As discussed in Chapter 1, this age group are within the liminal space, transitioning from childhood to adulthood (James 1986) or as it has been described “at the edge of no man’s land” (Hollis & Morgan, 2001 p45). Liminality designates a situation of ‘betwixt and between’ that traditionally occurs in transition rituals designed to transfer an individual from one social position to another (Arnett, 2006, Jaskulska & Mickiewicz, 2015; Janusz & Walkiewicz, 2018). This was evident for all the young male participants, although Helen – the only female and the oldest participant in the study – had reached maturity through developing

from being a teenager to a young independent woman and was in the process of building a life for herself and her partner, Stuart.

Consistent with other studies (Hajdarevic, Hörnsten, Sundbom, Isaksson & Schmitt-Egenolf, 2013; Lea, Gibson & Taylor, 2019; Gibson et al., 2013), many YP and their family/significant other in my study expressed dissatisfaction with some parts of their MM journey. Overall most participants in my study were satisfied with the hospital care delivery and treatment experience, albeit for some very brief. The main areas of dissatisfaction included insufficient information, the use of elaborate terminology which they did not fully understand and arrangements for aftercare, which is similar to previous literature (Farjou et al., 2013; Fern et al., 2013b; Gibson et al., 2013; Hedström, et al., 2004; Hokkanen, et al., 2004; Kelly et al., 2004; Kyngäs et al., 2001; Miedema et al., 2006; Olsson et al., 2015; Stegenga & Ward-Smith, 2009; Wicks & Mitchell, 2010).

In my study care delivery for YP with MM seemed to be disjointed and although some had contact with the TCT unit, which for one participant was adjacent to the specialist adult hospital, others had no access to these units until a further 'lump' or recurrence was diagnosed. No YP were treated within a TCT unit nor had any contact with other patients with MM who were going through the same experience as them, aside from Patrick and Helen when they suffered a second recurrence. The families also wanted some form of support and felt isolated in their psychological burden of trying to deal with MM and the waves of emotion that arrived when they thought of their child or loved one dying from this disease.

One young man Patrick, and his father Terry, appeared to be 'orphaned' within the healthcare system with no one prepared to decide on the optimal place of care for this patient. Patrick's place of care was dependent on his age as he was under 16 years of age at the time of his first and second diagnosis. He was still classified as a child and therefore had to be treated in a specialist children's hospital. The complexities of defining this age group can have an impact on the treatment pathway, defined by biological age, and sets the location of care as discussed earlier in Chapter 1. However, as Patrick was initially admitted to an adult ITU, as there were no beds within the TCT unit or children's ITU, this period of treatment

was confined to the adult setting. Families reported that the hospital environment was unsuitable for their child, with one mother, Eve, commenting on her son's treatment in a women's cancer breast unit. Another parent, Richard, commented about being in a busy surgical ward with older patients and all types of conditions. There were other concerns, such as travel and distance, to the specialist hospital, but most were prepared to travel for the 'specialist' cancer care. This was evident in Helen and Stuart's narrative, and although willing to travel, this meant Helen would spend a few weeks solely on her own as the specialist hospital was a significant distance from her home.

The treatment experience for those participants living with MM was different compared to the national guidelines for YP with cancer (NICE 2015; 2005; Scottish Government, 2016). Cancer care for TYA in the UK is consistently described as age-appropriate care, a concept that is said to underpin the culture of healthcare delivery specific for this population (Lea et al., 2018; Marris et al., 2011; Smith et al., 2016). Growing consensus describes it as inappropriate to deliver care to TYA in either child or adult environments of care (Kelly et al., 2004) or in settings not equipped to meet their psychosocial needs (McDonagh & Viner, 2006), yet these recommendations did not reach the YP and their family/significant other living with MM.

In December 2016, the Blueprint for Care was published in England, which provided a detailed account regarding the care requirements for the TYA population (Smith, et al., (2016). One of the key messages from this report was that all healthcare professionals caring for TYA with cancer should be knowledgeable regarding the developmental stages including social, emotional, psychological and physical development and all the needs of each individual should be assessed according to their developmental stage. Within my research, the treatment experience for MM appeared to be mainly provided by the CNS's, but once again, this was not consistent and was dependent on the personal attributes of the nurse. All other support was minimal and absent from their day-to-day lives. Models of care for YP with cancer in the UK have developed over the last 30 years to improve survival rates and provide an environment supportive to the unique needs of YP (Fern et al., 2013b; Lea et al., 2018; Pearce, 2009; Taylor

et al., 2013). However, two-thirds of YP with cancer in the UK do not have access to these 'specialist', 'age-appropriate' units and are treated either at their local hospital or a regional cancer centre alongside adults of all ages (Birch et al., 2013). This lack of access to specialist units was common to the YP and their family/significant other within my study.

Many studies have been carried out over the last twenty years where the TYA group is seen as unique with specific needs and place of care is an important issue (Fern et al., 2013b; Gibson et al., 2013; Hedström et al., 2004; Hokkanen et al., 2004; Kelly et al., 2004; Smith et al., 2007; Olsson et al., 2015; Wicks & Mitchell, 2010; Zebrack et al., 2014). More recent studies have focused on conceptualising age-appropriate care for TYA with cancer (Fern et al., 2013b; Lea et al., 2018). A mixed methodology study reporting on age-appropriate care reports on the complexities of defining age-appropriate care and suggest that there are seven core elements to their proposed model. This study was part of the BRIGHTLIGHT research study and was carried out by the research team. The types of YPs' cancer is not stated, but there were 17 YP and 29 healthcare professionals included in the semi-structured interviews from specialist and non-specialist hospitals. This study highlights that there was wide variation within the UK as to how we define age-appropriate care and where these YP have access to the specialist centres. Most YP who have MM are not cared for within this age-appropriate environment as their journey typically begins with the skin or plastic surgery outpatient departments. There was a lack of continuity and seamless care, with no one to share their experiences with.

A further finding related to the treatment experience was that for all the participants, the MM journey depended upon the knowledge, skills and competence of the healthcare professionals charged with delivering their care. Healthcare professionals in the UK are educated and trained to deliver high-quality, evidence-based care and to be able to listen and communicate with compassion (NMC, 2018). These are complex skills that can be lost in a pressurised, task-oriented environment with little time or energy available for emotional investment (Lavender et al., 2019). Research by Lavender et al. (2019), through a narrative inquiry with health professionals caring for AYA with bone

cancer, identified the importance of expertise and development for health professionals caring for this specific group of patients. The study explored one specific cancer and how AYA were prepared for inclusion within clinical trials. Once again, this study highlighted the importance of well-educated and well-trained healthcare professionals caring for the TYA cancer population, irrespective of the cancer they may have.

The participants in my study expressed concerns around the lack of any supportive care and the absence of healthcare professionals who knew about melanoma in YP, apart from some of the CNSs. Caring for YP with cancer and their family/significant other has unique challenges that attract healthcare professionals to work within this speciality (Gibson, Fletcher & Casey 2003; Gibson et al., 2012; Hedström et al., 2004; Kyngäs et al., 2001; McNally, Pouso-Lista, McLaren & Willis, 2017). Without education, training and a broader awareness of YP with cancer, healthcare professionals may not fully understand or be aware of the age-specific nuances that profoundly influence the YPs' experiences and that of the family/significant other. Some of these nuances include identity formation, gaining independence and being empowered to care for themselves (Soanes & Gibson, 2018). The participants within my study were desperate to have healthcare professionals who could support them through their journey, appreciating their age and stage in life as well as understanding MM.

Recent literature suggests that cancer education and training within the UK is inconsistent and is often embedded and delivered within HEIs and individual clinical services (Edwards, Kelly & Hopkinson, 2016; McNally et al., 2012). In the UK, education is mainly delivered through postgraduate education, predominately online, and is often seen as a specialist area of care (Jestico & Finlay, 2017). However, this type of learning does not suit all healthcare professionals, while others are seeking 'non-specialist' education and training, requiring this to enable them to care for YP out with the specialist areas of care. Evidence-based practice can transform and provide patients and their family/significant other with high-quality care (Smith et al., 2016; Gibson et al., 2012). A key priority identified by the Children and Young People's Health Outcomes Forum (DoH, 2007) is the need for a national approach to achieving a competent nursing workforce.

Collectively these recommendations have provided the platform for changes to nursing care and delivery. Recent literature has highlighted a drive to embed high-quality nursing care into specialist YPs cancer care (Scottish Government, 2016; Smith et al., 2016; NICE, 2005). There needs to be a continued effort to enhance the knowledge and competence of nurses who work with TYA with cancer in all types of services where they are cared for (Gibson et al., 2012; Smith et al., 2016; Taylor et al., 2016). Educational programmes need to facilitate professional's progression from novice to expert and provide for all levels of nursing alongside the interprofessional teams that also care for YP and their family/significant other (Benner, 1984; 2001; McInally, et al., 2017). The participants in my research fell through the 'specialist' care gap and therefore, like other YP with cancer may not have access to what is believed to be the best approach to their care.

Young people's cancer care has seen rapid advances in treatment and as survival rates continue to grow the need for expert specialist care and support increases (Lea et al., 2018; Gibson et al., 2012, Taylor et al., 2011). Although the number of YP with cancer in the UK is relatively small in comparison with the number of adults with cancer (Bleyer, Ferrari, Whelan & Barr, 2017; Fern et al., 2013a), it is recognised that cancer education and training for healthcare professionals is required to ensure patients and their family/significant other receive care from knowledgeable and expert healthcare professionals (NICE, 2005; Scottish Government, 2016; Taylor et al., 2016). Currently, in Scotland cancer education and training provision is varied and fragmented, and there is a need to establish TYA care within professional curriculums (McInally et al., 2017). A systematic review of the literature between 1996 and 2008 by Marris et al. (2011) examined how the experiences of young adults support or refute current policy during this time (NICE 2005). This review revealed that YP aged 13 to 24 years valued an age-appropriate environment along with support from others in their age group. The expertise of healthcare professionals caring for them was also seen as an essential aspect of their care.

The treatment experience of living with MM was unique for each participant in my study for many reasons. One young participant, Patrick, was treated with immunotherapy for his second recurrence and required more extended periods in

hospital than any of the other YP as the treatment had severe side-effects. There is little known about the lived experience of patients with MM undergoing immunotherapy and no literature concerning YP. Levy et al. (2018) conducted a feasibility study with 28 adult patients aged 41 to 84 years being treated with immunotherapy for advanced melanoma. This study found that patients with MM live within uncertain spaces, especially around the time of treatment. These patients attempt to normalise their lives after this event, engaging with family and other usual activities. This was similar to the findings in my study, even with a younger group of patients. Not one participant was treated within a specialist, age-appropriate environment, and as a result, many felt that the system was not designed to meet their needs. However, this was not the case for all, and in some situations, the care delivery was reported as excellent. As most were not hospitalised for prolonged periods, apart from Patrick and Helen, being with others of a similar age or with the same disease did not seem to matter to these YP.

Part of the treatment for YP focuses on transitioning of care between services. Transitioning from child to adult services or from hospital to home is recognised as a challenge for TYA care (Weston et al., 2018; McNally & Cruickshank, 2013). Although most were treated in an adult ward, apart from Patrick, who eventually transitioned to a TCT unit, the move from hospital to home was problematic for some. There did not appear to be any follow-up regarding pain or their wounds once they were discharged home. My research focused on this aspect of their journey, as some appeared traumatised from their surgical wounds. Paul, for example, expressed that overall, this was the worst part of his MM journey.

There are many models of transition in place across the UK, both within cancer and other chronic disease settings, and the age range varies according to local and government policy. There is, however, no clear evidence whether one of these transition models is superior to the others and there is wide variability across the country in the models used (DoH, 2007, NHS Improvement, 2011). Furthermore, healthcare professionals sharing their experiences of transition through different practice systems are invaluable and highlight the differences in the care delivery regionally and nationally (Weston et al., 2018). Within the specialist cancer services across Scotland, the transition models used appear to depend on the

diagnosis and where the YP are treated (Royal College of Physicians of Edinburgh 2008; McNally, 2013).

A cancer diagnosis and the associated treatment during this critical transitional stage of normal adolescent development adds extra complexity to illness-related challenges. The Improving Outcomes Guidance (IOG) for Children and Young People with Cancer suggests YP with cancer should benefit from the expertise of specific cancers and supportive healthcare professionals (NICE, 2005). To support YP with MM, specialist healthcare professionals, and approaches to care delivery are required. Care should be age-appropriate, flexible, and individual to meet their specific needs. Following their cancer treatment, YP can feel disempowered, vulnerable, and experience a loss of personal confidence. Interventions that facilitate empowerment can help improve health-related quality of life and their ability to cope (Kygäs et al., 2001; Wu et al., 2009).

This part of the journey provides strong evidence that the MM journey had interrupted the lives of the YP and their family/significant other. During the journey, the specific treatment experience differed for each young person and was dependent on their age at the time of initial diagnosis. Two YP were aged under 19 while three were over 20 years old and this may have contributed to the different experiences. The delivery of high-quality care, and the associated treatment experience, required competent healthcare professionals who are knowledgeable about the immediate and long-term implications of MM treatment journey. As YP with this disease begin their journey out with specialist cancer services, the care delivery for this patient group and their families/significant other requires to be seamless, ensuring there are links between services, working better together than apart. Healthcare services need to ensure that clearly defined care pathways and guidelines that are specific to the needs of YP are accessible. Remarkably, although MM is a serious life-threatening disease, the YP and their family/significant other all felt as though they were different from other patients with cancer and therefore did not always fully comprehend the seriousness of the disease.

5.4.4 Time to Live

The YP's scars, both physical and emotional, were a constant reminder of what they had experienced and endured, along with the other trials and tribulations that the MM had presented to them. These scars now represented a crucial part of their present and future identity, and most of the YP had come to terms with this, as had their family/significant other. Both physical and emotional scarring were present and were associated with the long-term side effects from the treatment and mirrored by the participant stories of how they survived and lived with MM. The YP described this scarring by referring to them as 'battle scars' and has much in common with post-traumatic stress disorder (PTSD) symptoms (Al Omari Wynaden et al., 2017; Al Omari & Wynaden 2014; Madan-Swain et al., 2012).

The YPs physical and emotional scarring reminded them constantly about the disease, its seriousness and their fragility. Although the YP could recall having hope and the ability to move forward after having the mole excised and surgery to remove the infiltrated disease, the procedures had left severe scarring. These scars represented a key part of their present and future identity, although most of the YP had tried to come to terms with them. For the family/significant other, they were aware of how uncomfortable these scars were for their loved ones and tried hard to distract their attention from the physical scarring.

In common with Soanes & Gibson (2018), my study found that YP reported a desire to maintain their sense of self and protect their identity. It was difficult for the YP, in particular, to detach themselves from the scarring. A systematic review of the psychosocial outcomes for adult patients with advanced melanoma carried out in Brisbane, Australia, found that altered body image had left the patients feeling unprepared for the impact of the surgery and distressed by their appearance (Dunn, Watson, Aitken and Hyde, 2016). Although this qualitative literature review concerned the older patient with MM, the mean age ranged from 41.2 to 69.6 years. The findings are relevant to the YPs experiences within my study. The YP reported that although satisfied that the mole had been removed, they were conscious that the scarring had disfigured them as a result of the surgery.

Young people and some of the family/significant other required psychological support to improve their overall well-being, social functioning and mental health during and after their MM experience. Most of the participants had strong supportive networks through families and friends, but further support from expert professionals would have been beneficial. Aldiss et al. (2019) reported on a UK wide study where YP aged 13 to 24 years, along with families, friends, partners and professionals were asked through a survey design to identify and rank the key priorities for YP with cancer. Ten key priorities identified, with the main priority identified being psychological support during and after treatment (Aldiss et al., 2019). This is an area of care that is underdeveloped and one that is often forgotten about in comparison to the delivery of physical care. Recently within Scotland, YPs mental health has been raised as a critical priority, and more needs to be done for YP who are experiencing cancer along with mental health illness (Scottish Government, 2018). These needs must be considered for this patient group when they are at a junction in their lives, and where mental illness may have been a challenge for them prior to MM (Marshall, Grinyer & Limmer 2018; Wicks & Mitchell, 2010). In my study, two the YP had lived with a mental health illness before the cancer arrived. For the family/significant other living with MM was like being on an emotional rollercoaster simply because their experience of MM changed all the time, combined with having no professional help to ease them through the difficult parts of their journey. Young people and their families/significant other need support with all aspects of the MM diagnosis, with a greater focus on psychological care.

Supportive relationships were critical to the YP's MM journey. They all viewed their MM experience as a shared journey with family/significant other and friends. As most of the YP lived at home with their family/partner, it was their parents/loved one who became their primary carer, supporter, adviser, advocate and friend along this journey. This journey with MM had brought new and different meanings to their lives and forged a different path for them. In moving forward, they had not been defeated by the disease and continued to make plans for the future, despite the interruption from the MM diagnosis.

The YP expressed that they had acquired a greater awareness of themselves, and they were checking their bodies frequently to try and avoid any worry about future recurrences. The worry of recurrence would remain as an almost permanent presence in the lives of some YP and their family/significant other, but they were still able to move forward with their lives. Given the untimely interruption in their lives, a critical point in the journey was to regain a sense of control over their lives as a means of attaining long-term adjustment and well-being. Psychosocial support for patients with MM would assist individuals in retaining or returning to function in significant social roles, such as a spouse, student, worker, or friend. Successful interventions would enable YP to overcome the detrimental impact of a health crisis and strengthen the internal and external coping resources available to them. However, despite the successes in medical treatment over the past 40 years, a full range of psychosocial services is not readily available to all patients diagnosed with MM and living with this disease.

Although most of the participants would have welcomed support from others who were “in the same boat” as found in a study by Kelly et al. (2004, p847), support did come from various other places including family and close friends. This was similar to the findings in the research carried out by Al Omari & Wynaden (2014), Wu et al. (2009) and Wicks & Mitchell (2010), where support from family and friends was a fundamental coping mechanism. Friends were a vital source of support for the participants. The nature of friends' responses to the MM helped the YP through the disease, the YP were grateful they had stayed the course of the journey with them (Davies et al., 2018; 2015; Wu et al., 2009). Families were also relieved that their friends had not deserted them. This, however, was not the case for all and for Patrick, his friends had disappeared. He found solace in the father/son bond and through his small extended family. Adolescence is a critical period in psychosocial development and autonomy; peer group acceptance and bonding are fundamental in the transition period from adolescence to adulthood (Grinyer, 2007). A lack of peer support during this time may prevent the young person attaining a sense of belonging (Mulhall et al., 2004). The need for peer support was clearly articulated in this study, but for some (Patrick and Helen) they found this from their family/significant other.

Participants in my study were mainly positive and optimistic throughout and looked forward to their future, albeit on a different path and living within the shadow of MM.

The notion of trying to achieve 'normality' has been identified as necessary to TYA during the cancer experience (Taylor et al., 2013; Stegenga & Ward-Smith, 2009) but it is not clear what this 'normality' is for the YP and their family/significant other. Within my research, they all recognised that their life had changed but remained aware of what was important to them. Although all strived to achieve some normalcy, for some, the disease and treatment had a continuing impact on their lives. Most had completed treatment but were still receiving regular follow-up checks, and there was a constant worry that the MM would return. Many saw this as a time to re-align and move forward as life was more than cancer, and thoughts of the future turned to their career, setting up a home or going to University. The life they had once known had gone, and they were experiencing a new and unexpected journey. All the participants felt stronger both as a family/partnership and that this experience had drawn them even closer. For some, close friends also played a crucial role in providing emotional support while for others, it was their family/significant other. When reflecting on their MM experience, it was clear from the YP and their family/significant other that improvements to certain aspects of the care delivery would have alleviated many of the stresses and fears in their MM journey.

Findings from my study reinforce previous studies (Hokkanen et al., 2004; Salanterä 2004; Kumar & Schapira, 2013; Stenenga & Ward-Smith, 2009; Woodgate, 2006) that stress the importance of having strong supportive relationships. These relationships helped the YP cope with their cancer (Davies et al., 2018; Smith et al., 2007; Taylor et al., 2018; Woodgate, 2006) and move through their journey. These supportive relationships included family, friends and the CNS. Family-centred care has, for many years, been central to the nursing practice for CYP across the UK and some parts of Europe (McInally & Cruikshank 2013). Reflecting the intense emotions experienced with MM, many YP worried about how the disease had impacted on the emotional and psychological wellbeing of their siblings. Previous literature around YP with cancer have taken

into account how this impacts on siblings (Eiser, 1993; Grinyer, 2007; McDonald, Patterson, White, Butow & Bell, 2015). Parents provide the most important social support, but as the disease had an impact on the whole family, it was clear that they all needed support (Grinyer, 2007, 2009).

While the importance of strong family relationships was a crucial part of the MM experience, these individual relationships were unique, sophisticated and fluctuated over time. During my research, one young man, Patrick, who was discussed previously in Chapter 4, was the only participant who was a child at the time of his initial diagnosis. At such a young age, Patrick lacked the maturity, knowledge or emotional stability to deal with the disease and was content with his father making all the decisions for him. The other YP within the study had all reached a level of maturity that allowed them to make their own decisions in consultation with their family/significant other.

A further study by Davies et al. (2018) suggests that the family and those close to the YP during their cancer journey, are undeniably important in their lives during this time. Through a longitudinal multiple exploratory case study design, utilising observation and documentary analysis, five YP aged 16 to 24 years were interviewed three times during their journey along with parents, carers and healthcare professionals. The experience of the significant other/loved one was essential and seemed to play the same role as the family, although they had an additional element to their relationship as they were romantically involved. More research is required into these dynamic relationships and their impact on the YPs experiences and their treatment/care-related decisions along the cancer journey (Kyngäs et al., 2001; Davies et al., 2018; Drew, Kable & van der Riet, 2019).

This study provides evidence to support that living with MM involved the whole family/significant other and the relationships had a positive impact on living with the disease for all the participants who could recall the closeness and emotional bonds that were now stronger than they had ever been before. These relationships provided encouragement, positivity and strength to continue in living with MM. From the evidence gathered sharing the burden of melanoma-related worry lessens the worry and fear associated with the disease.

5.5 Strengths and Limitations

The findings of this study have been drawn from in-depth qualitative interviews with five YP (n=5) and five family/significant other (n=5) living with MM in Scotland and offers a unique perspective from the participants. The findings were not intended to be generalisable beyond this setting, but have relevance and significance to other researchers, healthcare professionals and services who care for YP with MM and their family/significant other. As such, at the time of writing, this was the first in-depth study to describe the experiences of YP and their family/significant other living with MM using an IPA approach and makes a unique contribution to knowledge.

This study and the underlying IPA approach has many inherent strengths. Firstly, the individual interview and dyad approach added a multi-perspective design, allowing for the shared experience and the phenomena to be fully captured and understood (Larkin et al., 2019). This design allowed for the YP to select their family/significant other, who were involved in living with MM, and whether they opted for an individual or shared interview. However, in carrying out the dyad, I was mindful to ensure that no individual was more dominant or influential than the other. Although small, the sample size of ten fully complied with the IPA methodology recommended by Smith et al. (2009). Through following the step-by-step IPA approach, I maintained a rigorous approach to the data to ensure I had captured the voices of all my participants.

Secondly, my study was the first to explore the experiences of one specific type of cancer, MM, and to consider the impact of this disease on the patient group and their family/significant other in great depth. This detailed analysis has produced rich results and allowed the researcher to trace the ebb and flow of the cancer journey through the experiences and words of the individual participants.

Thirdly, this thesis has made a strong and unique contribution to existing knowledge, highlighting the understanding required to care for YP with MM and their family/significant other in the most effective and holistic ways.

However, my study does have limitations. Firstly, obtaining ethical approval at the beginning of the study for my preferred age bracket was the immediate challenge. At the outset, I wanted to include YP in the 13 to 24 years of age bracket, although the number of children under the age of 15 years diagnosed with MM in Scotland per year was exceedingly low, with only one child being diagnosed with this disease in 2015 (ISD, 2019). The challenge was related to the actual ethical approval process involving both ENU and NHS Scotland. The documentation from each organisation was arduous and complex (NHS Research Scotland, 2020). In Scotland, YP under 16 years of age are considered children, and from the outset, it proved difficult to obtain informed consent within the available timeframe (Scottish Government, 2014). Nevertheless, focusing on the lower age bracket would have been an addition to this study as it was important to capture the younger voice. Ultimately, after careful consideration, and discussion with my supervisory team, it was decided that the age bracket range would be increased to include those aged 16 to 26 years. This change in the inclusion criteria allowed ethical approval to be sought and granted relatively quickly and allowed data collection to begin.

Secondly, although the sample size of ten was appropriate to an IPA approach, only one young female and one significant other (her male partner) participated in the study. With the reported incidence of MM in young females greater than among the male population (CRUK, 2019b; ISD, 2019), it would have been beneficial to have captured a broader female perspective on the disease. Despite recruiting an additional two female participants into the study, neither attended their scheduled interview and although alternative telephone interview options were offered, these were also declined. As part of the ethical approval, it was recommended that the interviews take place during the outpatient appointment to minimise the disruption to the participants' lives. However, if another venue and time, more suitable to the young females, had been offered, this may have supported and encouraged them to participate in the study. The experience of the significant other in the MM journey was also under-represented in my study. All the young participants in the study had the option of selecting a family member or their significant other to join them in the interviews. To my surprise, the vast majority of YP opted to select a parent to participate in the interview process. As I wanted to reflect the voice of all

the participants truly and accurately, there was no obvious way to mitigate these circumstances. Any future research that seeks to build on the results of this study should endeavour to make the recruitment of children, females and significant others a priority.

Other limitations associated with my study mainly lie within the integral limitations of IPA as a research approach. The role of language and emphasis in collecting data cannot be underestimated. Deriving meaning from the research depends upon the interpretation of individual narratives, stories, metaphors and nuances. The primary purpose of IPA is to gain insight into the lived experience, but that insight is always intertwined with language and the researcher's understanding of the language used by the participants to convey meaning. To assist with capturing the voice of the YP and interpreting their true meaning, alternative data collection methods could have been used (Larkin et al., 2019, Polit & Beck, 2010). For example, allowing participants to keep an audio diary over a suitable period may have reduced their anxiety or stress associated with the interview process. This may have also helped provide deeper recollections of their experience recorded in their natural, day-to-day language. This, however, does depend on the ability of the individual to clearly articulate their experiences and emotions. This is a dependence common to all qualitative forms of enquiry, including IPA (Smith et al., 2009).

Questions can also be asked whether the IPA methodology can accurately capture the experienced reality and the associated meanings rather than just opinions, memories and reflections of it. As IPA is a philosophy associated with introspection allowing the researcher to explore his or her experiences through 'phenomenological meditation', IPA as a research approach relies on the accounts of participants and the experiences of researchers (Smith et al., 2009). This depends on both the participants and researcher possessing the requisite communication skills to communicate the nuances of experiences successfully. Consequently, phenomenological research relies on the most eloquent individuals and this may be particularly true in my study, reflecting those individuals who were best able to elucidate their experiences. Indeed, concerns over their ability or confidence to clearly express their experiences orally may explain why two

participants withdrew from the study after initially agreeing to take part. As noted earlier, alternative data collection methods such as an audio diary may have helped minimise this concern and should be used in future studies with YP and their families/significant other in this context.

Finally, the sample population of ten (n=10) generated copious amounts of rich data which needed to be organised, collated, analysed and then interpreted. Indeed, the sample size exceeded that recommended by Smith et al. (2009). At the outset, this presented challenges for an initially novice IPA researcher. However, following the Smith et al. (2009) step-by-step approach provided the necessary guidance, structure and support to complete the data analysis and ensure its integrity and coherence.

5.6 Implications for Research, Practice and Policy

Based on the findings presented in Chapter 4, I now make several suggestions for research, practice and future policy.

5.6.1 Research

The main aim of my study was to establish what it meant to live with MM and to record the experiences of the YP and their family/significant other. The IPA approach has allowed rich data to be collected and analysed to answer the original research aim and questions in great depth.

As a direct progression from my study, new research would further expand the understanding of this specific participant group living with MM. My plan for further research includes exploring the following questions:

1. Are the findings presented within the thematic structure an accurate representation of the participants' journey with MM?

This research will gauge the relevance of the thematic structure, presented in Chapter 5, in relation to the YP's actual lived experience. This question will be fully answered through the planned public engagement event scheduled for

March 2020. Additional data will be collected from the participants on their journey since 2017.

2. Do YP under the age of 16 years and females diagnosed with MM have any additional or different experiences and expectations over and above those identified in this study?

Children and young people under the age of 16 years and young females were underrepresented in my original study, and their specific, unique experiences have been missed. Owing to the small number of children diagnosed with MM in Scotland each year, any future research would be expanded across the four nations of the UK to ensure a representative sample size of younger participants, with specific attention paid to the experiences and voices of young females. The exact research protocol to be adopted would require careful consideration but is likely to feature a combination of survey, audio diaries and semi-structured interviews as an effective way of collecting data on this scale.

3. How do the family/significant other inter-relationships change when the YP experience a recurrence of MM with a poor life outcome?

The family/significant other cannot be separated from the YP's MM experience. The research would explore the emotional and social impact of an MM recurrence within the family/significant other and include the impact on siblings and close friends. With no available literature, this research would add to the body of knowledge specific to this disease.

4. What are the healthcare professional's perspectives on the findings?

During ethical approval with the NHS Boards, I was asked to return and relay my findings and plan to complete this in Summer 2020. I plan to explore the healthcare professional's perspectives on the core conceptual thread, 'Life Interrupted' metanarrative, and the key findings. Alongside the NHS healthcare professionals, it would also be beneficial to explore these findings with the GP and to capture their experiences on dealing with YP who come to their surgery with suspicious moles.

5.6.2 Practice

It is only by focusing on the experiences of YP, and their family/significant other, living with MM that should see improvements to healthcare services designed to meet the needs of this patient group. Anecdotal evidence suggests and is confirmed within my study, that YP with MM experienced fragmented service delivery and insufficient support, potentially leading to poorer patient outcomes. Obtaining an early diagnosis is crucial to identifying the stage of this disease and enabling swift treatment to help prevent metastases (Ali et al., 2013). How YP and their family/significant other receive this diagnosis and the supporting information provided, also needs to be reviewed in light of the evidence within my study. Improvements in communication and information sharing would help introduce an improved overall experience, given how profound this experience is for YP and their family/significant other.

As YP with this disease begin their journey outside specialist cancer services, the care delivery for this patient group and their families/significant other require links between services, working better together than apart. For example, stronger links between the TCT units and health and social care professionals and Skin Cancer Services. Being able to recognise and deal with the disease can be challenging, and mechanisms need to be in place to support YP and their family/significant other psychologically including, for example, support groups and online spaces specifically for the YP with MM. Currently education programmes for young people in schools are being reviewed with the face to face contact being replaced with digital learning (TCT 2020). A series of podcasts would support YP and their family increasing their awareness, knowledge and support for melanoma. This would support the lack of physical, emotional and social support for this patient group and this disease, often resulting in feelings of isolation.

5.6.3 Policy

This study emphasises the need for greater awareness, knowledge and understanding about skin cancer, especially for CYP. The Scottish Government are in the process of updating their existing policy for CYP with cancer and are

inviting contributions from leading clinicians and nursing professionals. Part of my dissemination strategy will involve the creation and circulation of a short key findings paper to prominent policymakers, senior clinicians and nursing professionals. This approach will include sharing the key findings with the MSN National Clinical Director, Professor Hamish Wallace. Education must continue within schools, colleges, and the media to increase awareness of skin cancer and prevention, for both the YP and their families. This may help ensure that prompt medical attention is sought at the appropriate time. Other countries, such as Australia, have already led the way with the effective public and media campaigns such as 'Slip, Slap, Slop' (Montague, Borland and Sinclair, 2001). Society also needs to reassess its common definitions of beauty in this age group so that in time the demand for tanning studios may reduce making these as culturally unacceptable as smoking or drink-driving (Murray & Turner, 2004).

Young people with this type of cancer do not necessarily feel unwell. Therefore, education regarding the full symptom spectrum associated with MM must be mandatory for all healthcare services and professionals, especially in primary care settings which are the first port of call for YP with suspicious symptoms. This broader understanding of the disease, wherever it presents within the health service, can help signpost the individual to the most appropriate care provider.

5.7 Conclusions

The lives of YP matter; their experiences matter; their futures matter; and that of their families/significant other matter. As a nurse, academic and researcher, this study confirmed five significant contributions to knowledge and understanding about YP living with MM:

1. The study has addressed the gap in the existing literature around the experience of YP living with MM.
2. No other studies have explored one type of cancer experienced by YP, such as MM, in this level of detail.

3. This study included the critical role played by the family/significant other in supporting the YP in their MM journey and the interconnection and inter-relationships that exist.
4. This is the only study (at this time of writing) that has used IPA to understand YP and their family/significant other living with MM and to illustrate the depth of experiences.
5. The use of a novel multi-perspective design within the IPA approach that builds on the recurring hermeneutic practice.

From these five significant contributions, my thesis makes a claim to originality on two grounds: (1) empirical; (2) methodological. Development of theory cannot be claimed as this is not an accepted feature of an IPA approach.

There have been no other studies, utilising an IPA approach, that have explored the experiences of YP living with MM or that of their family/significant other. Perhaps, as a paediatric nurse first and foremost, the needs of the family have always been of significant interest to me as part of the YP's life journey. The conceptual representation shown earlier in Figure 5.2 will help healthcare professionals improve their understanding of the multifaceted and dynamic physical, emotional and social needs of YP and their families/significant other in living with MM. The importance of the complex interplays between the YP and their family/significant other and the underlying emotional bonds is clearly illustrated within the visual representation. Ultimately this enriched understanding will contribute to improving the care pathways and management for this patient group. It will also drive the improvement of care delivery for this specific disease in order that this patient group is provided with the same access to service delivery as other YP with cancer.

The YP and the family/significant others experience of MM before diagnosis was limited and not a disease that they associated with themselves or their child/loved one. The general public and healthcare professionals require greater awareness, knowledge and understanding about skin cancer and in particular melanoma.

From this study, it cannot be concluded that a diagnosis of MM in the YP group was a direct result of overexposure to UV light. Apart from one young person who had been 'sunburnt' as a child, all others had protected their skin. The literature highlights that sunburn as a child increases the risk of melanoma and safety interventions are recommended throughout life (McNally et al., 2014; Tripp et al., 2016; Ali et al., 2013). Most of the YP were ambivalent and bewildered with their changing mole, and although had sought medical advice straight away, delay in diagnosis was evident from the inaction of the GP. All participants in my study would have valued contact with other patients with the same disease and care that was similar to other YP who are experiencing cancer. The perception of MM, and its severity, is different from other cancers and did impact on the experience of YP and their family/significant. This may relate to a lack of knowledge and understanding from healthcare professionals and the general public.

At the beginning of their MM journey, all the participants experienced an overwhelming sense of their lives being interrupted. Most were looking forward to their lives, studying hard to accomplish good grades and building their futures. This interruption, however, fluctuated along the life continuum and on some days their lifeworld flowed as smoothly as before, but other days were consumed with uncertainty and fear. This insight into the actual lived experience of the YP and their family/significant other substantiates Eatough & Shaw's (2019) lifeworld research.

The increase in TCT units across the UK and in particular Scotland has not necessarily improved the experience of everyone in the YP age group or eradicated the 'lost tribe' described by Michelagnoli et al. (2003). Indeed, for the YP in this study, there was limited access to these units or the supportive care element that they provide. However, for the participants in this study, the treatment environment was not the primary concern. It was the lack of specialist support from other healthcare professionals and other families "like them" who understood the impact of the disease. It is vital that YP and their families/significant other have someone to communicate with and share their concerns. In order for healthcare professionals to better understand how to support YP and their families/significant other at the time of discovery, diagnosis, treatment and adjusting to living with MM,

requires a change in attitude and approach within the broader healthcare profession and the patient group themselves.

This study has revealed that the diagnostic process for investigation of a 'suspicious' mole, was a stressful experience for many YP and their family/significant other. While a Skin CNS provided emotional support for the participants during the diagnosis of MM, they were not always a specialist for YP. The findings of this study suggest that all patients might benefit from increased psychological support and information provision at the initial clinic attendance and throughout the treatment journey.

Melanoma, in common with other cancers, has a significant psychological effect on YP and their families/significant other. This study also found that this disease has a profound effect on siblings and close friends, although this is an area of the experience that this study was not able to capture but is an area that requires further exploration. The visible nature of cancer, in general, seems to be necessary with participants expressing frustration and anger that the 'skin lesion/mole' was not recognised sooner. Prognosis and individual factors were all essential aspects in their ability to cope with the diagnosis, and all reiterated that support, information and a clear treatment plan, would support the overall journey in living with MM.

As seen throughout this thesis, MM remains one of the most prevalent cancers in YP worldwide, and the reported incidence continues to rise, despite global advances in cancer treatments, management and public awareness over the last 50 years. With the incidence also accelerating across the world, including Scotland and the rest of the UK, there is a pressing demand to improve the experience, diagnosis, treatment and understanding of this patient group. This study has illuminated the experiences of the YP and their family/significant other and should have a positive impact on future research, practice and policy. The results seen here should be regarded as the beginning rather than the end of this change in approach to dealing with MM.

For the YP and their family/significant other, the MM experience interrupted their expected life journey in many ways, resulting in a series of negative and, for some, positive life-affirming experiences. This overall experience is best summarised in the words of C.S. Lewis which opened this thesis, “The truth is of course that what one calls the interruptions are precisely one’s real-life” (Lewis, 2008 p.97).

Epilogue

"There are far, far better things ahead than any we leave behind".

C. S. Lewis, in a letter to his friend Mary Shelburne on 17th June 1963
as she was dying, five months before his own death
on 22nd November 1963 (Hooper, 2006 p.90).

I began this thesis by relating my professional and personal interest in, and experience of, living with MM in the Prologue. My primary motivation has been to hear and honour the voice of the individual participants and provide a scholarly platform for their stories. Throughout this journey, I have searched for answers to existential questions and human experiences which prompted my original research questions of "What are the experiences of YP and their family/significant other living with MM?" While the preceding Chapters have provided me with innumerable personal and professional opportunities for learning and reflection, I aimed to gain an understanding of YP and their family/significant other living with MM.

Conducting an IPA study was time and labour intensive, but it was also creative and thought-provoking (Smith et al., 2009). This involved focused concentration in listening and reading the transcripts, ensuring I was interpreting the participants' experiences in a way that captured the whole while preserving the individual voices. During the data collection process, I had to continually remind myself that I was not the 'nurse' but the 'researcher'. For this to be successful, I had to anchor myself firmly within the research role and be guided by my supervisory team throughout this part of the PhD journey. Often, this was a lonely and emotional experience, especially days where I had to immerse myself within the data and determine the meanings of what the individual participants had conveyed. The continuum of research skills set out by Smith et al. (2009) have clear guidelines which offer useful information at all levels to learn and develop the craft of IPA, and I followed this protocol.

Throughout this research, I kept a reflexive journal and audio diary which have helped me to explore the experiences and understandings in more depth. Initially,

my data analysis was descriptive, particularly in the early stages of data collection, however later, when I became absorbed in analysing the data rigorously and following the key steps by Smith et al. (2009), these notes became much more detailed. I consider that using IPA helped to deepen my knowledge and skills of analysis as this encouraged free associations to develop my creativity in the early stages of analysis, and I found this to be particularly liberating.

In addition to the above, I became a member of the IPA Scottish Interpretative Phenomenological Analysis Interest Group (SIPAIG) who meet from January to April each year. This group offers a relaxed, informal, supportive environment for those engaging in IPA research. Each meeting comprised a combination of workshops designed to support students in each step of the IPA process coupled with an open forum for advice, guidance and discussion on our work. Several keynote presentations allowed me to meet experienced IPA researchers, such as Michael Larkin and Paul Flowers, and learn about their work. These workshops have supported my grounding of the IPA approach, which is distinct from other qualitative approaches due to the combination of its inductive, idiographic, interpretative and reflexive nature.

Strategic dissemination of my work has taken place throughout the PhD journey. I have continuously presented my work to a range of audiences, including colleagues within ENU, CNSs, nursing students and researchers as well as health and social care specialists working within CYP and TYA. The primary purpose of this approach was to share the key learnings as the PhD progressed and that ensure my work was appropriately considered and recognised, allowing the participants in my study to voice their experiences.

Dissemination of my work involved several conferences, public engagement events and publications over the last three years and this approach to sharing my research will continue. This strategy is summarised in Appendix 19. My approach to the dissemination of my research has been strategic and focused on sharing key knowledge to drive forward the design and implementation of research, practice and policy for this important patient group and their family/significant other.

Dissemination began with the presentation of my preliminary results at the TYAC Conference in June 2017, where I received an award for runner-up 'best infographic poster'. In November 2017, I was instrumental in leading the collaboration with Macmillan Cancer Support, Youth Theatre Arts Scotland, ENU School of Health and Social Care (Cancer Collaborative Theme) to deliver a high-profile public engagement event with an original performance inspired by the findings of the BRIGHTLIGHT research. This event was held over three nights at the famous Traverse Theatre in central Edinburgh. As an organiser for this event, I was able to invite the participants from my study to attend. Making contact through their CNSs (who were also invited) the study participants, along with the various CNSs, took part in the roundtable discussion immediately after the final performance. Afterwards, they informed me that that had found the performance emotional, believable and true-to-life and found great solace and comfort from being able to network with other YP with cancer and discuss shared experiences. As part of sharing the knowledge and understanding gained from the BRIGHTLIGHT research, critical policymakers from the Scottish Government, the NHS in Scotland and MSN, including the First Minister and Health Minister, were invited to attend and hear first-hand about the experiences of YP with cancer. Examples of this work can be seen in Appendix 20. The receipt of a Stephen Sutton Award allowed me to attend the Adolescent and Young Adults Global Accord International Cancer Conference in Atlanta on 5th December 2017, where I presented my updated preliminary findings. Both conferences helped with the early dissemination of my work across international audiences of health and social care professionals, researchers and service users.

In early 2018 as part of the Post Graduate Research (PGR) conference, I gave an oral presentation on my research to other PhD students, researchers, colleagues and nursing students. The feedback received was very complimentary and encouraged me to continue on my PhD journey. Examples can be seen in Appendix 21. During the year I was approached by Professor Alan Glasper, Chief Editor of the journal *Comprehensive Child and Adolescent Nursing*, to submit a position paper around YP with MM in Scotland which was published later in 2018. This can be seen in Appendix 22.

In March 2020, following on from the positive experience of the BRIGHTLIGHT public engagement event in November 2017, I invited all my study participants and their siblings to a second public engagement event. Additional funding and ethical permission were sought and approved prior to the event. This event was a participatory workshop where I presented my PhD findings and gathered additional data around the findings through a series of moderated and facilitated discussions. The discussions explored the credibility and relevance of my findings and to establish how their own journeys had progressed in the intervening three years since I first began collecting data. More details about the workshop can be seen in Appendix 23.

I have continued to submit abstracts to showcase my work through national and international conferences such as the *British Psychosocial Oncology Society* event in Edinburgh in February 2020, The *Society of International Paediatric Oncology* conference in Ottawa, Canada in October 2020. I am the lead for the EONS Education working group, and a teaching session is being arranged through the European School of Oncology (ESO) as an e-session to take place in August 2020. Part of this role is to develop and deliver a series of podcasts for health and social care professionals caring for children and young people with MM.

I also plan to build upon my research portfolio by submitting three empirical papers from my thesis. My first literature review was registered through Prospero (CRD42017084148) and will be part of the dissemination for my second literature review in *Enfermeria-Clinica*, a Spanish peer-reviewed journal. Recently the Enfermeria-Clinica editor has approached me to contribute to a special edition focusing on Teenagers and Young People with Cancer. This is scheduled for publication in June 2020. In addition, a review paper on the methodology and novel perspectives (individual and dyads) used within the IPA methodology will be submitted to *Frontiers in Psychology* in mid-July 2020. Lastly, I will be preparing a paper on my findings for the *European Journal of Oncology Nursing* in September 2020. Going forward, I will continue to build upon my practice NHS links and collaborative membership working with cancer charities around the UK and internationally to disseminate my research findings further.

Each step in this PhD journey has presented me with new personal challenges, from exploring theoretical debates into the nature of reality to the more practical development of effective interviewing and analytical skills. Significantly, my five-year immersion in the research process has also compelled a timely re-examination of my professional practice as a nurse, academic and researcher. During my PhD journey, I stumbled across the following song by Paul Weller. The song, *True Meanings – Aspects*, is fitting for IPA and how we try to make sense of our life and our world. However, the true meaning for its use within my thesis is that this artist was my brother Keith's favourite growing up as a young teenager in the early 1980s. At this time Paul Weller was the lead singer of *The Jam* and left a lasting impression on his young adult life. This song played a vital role in my PhD journey. Its lyrics shared below as the final words of this thesis, spoke to me on a personal, emotional level. I listened to this song frequently.

Increasing my knowledge around evidence-based practice and research has developed my critical thinking, especially around the care for children and young people with cancer, and in particular YP and their families/significant other living with MM. For now, this is the end of this story. This thesis is the first step in understanding the meanings and patterns in YP's and their family/significant others' experiences of living with MM. From here, through the dissemination of my findings and future research building on the foundation I have laid, my hope is that a new wave of research can be carried forward to ensure that healthcare is appropriate and accessible from the moment YP ask 'Is it Serious?'

"True Meanings – Aspects" by Paul Weller.

It's not in the way it's not in your hair
You won't find it under your chair

And as long as the wind blows
The tides flow along

It's not in a hollow or pieces of wood
I don't see it anywhere no more

Under a blue sky on a new wave
In a new world today

And as long as
The wind blows
The tides flow along

Crippling aspects
Of life with no rhyme
Nor that of reason or that of time

Under a blue sky
On a new wave
In a new world
Today

***To find true meanings
And patterns in things
Symbols in making
These moments exist***

It's not in a holler
Not in a scream
You won't find it under your feet

And as long as
The wind blows
The tides flow along

It's always inside you
As old as the sun
It's holding the answers as new as the young

Under a blue sky
On a new wave
In a new world today

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Appendices

Appendix 1: Disclosure Scotland – Basic Disclosure

STRICTLY PRIVATE AND CONFIDENTIAL

Disclosure

SCOTLAND

BASIC DISCLOSURE

Criminal conviction certificate issued under section 112 of the Police Act 1997

MRS WENDY MARGARET MCINALLY

29 [REDACTED]

BE [REDACTED]

ED [REDACTED]

MI [REDACTED]

EH [REDACTED]

SC [REDACTED]

Disclosure Number: 20 [REDACTED]

Date of Issue: 02/05/2016

Page 1 of 1

Applicant Personal Details

Surname: MC [REDACTED]

Forename(s): WE [REDACTED]

Date of Birth: 25/0 [REDACTED]

All basic disclosure certificates are issued under section 112 of the Police Act 1997. A certificate either contains information about every conviction of an applicant or states that there is no such conviction. Conviction takes its meaning from the Rehabilitation of Offenders Act 1974, but it does not include any spent conviction. The Rehabilitation of Offenders Act 1974 sets out rehabilitation periods after which convictions may become spent; different rehabilitation periods apply in England and Wales and in Scotland.

For an application where the home address of the applicant is in England or Wales, the application has been processed under the version of section 112 of the Police Act 1997 and the rehabilitation periods in section 5 of the Rehabilitation of Offenders Act 1974 that apply in England and Wales.

For an application where the home address of the applicant is in Scotland or in a country overseas Great Britain, the application has been processed under the version of section 112 of the Police Act 1997 and the rehabilitation periods in section 5 of the Rehabilitation of Offenders Act 1974 that apply in Scotland.

Convictions

The applicant has no convictions for disclosure.

END OF DISCLOSURE

Barcode

005250302C81

23767915

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Appendix 2: Clinical Research Access – NHS Lothian

NHS Lothian –
University Hospitals Division

8th December 2016

Ms Wendy McNally



Research &
Development

Room E1.16
The Queen's Medical
Research Institute
47 Little France Crescent
Edinburgh
EH16 4TJ

Tel: 0131 242 3330

Dear Ms McNally,

Letter of Clinical Research Access – only valid until 12th December 2017 for study number 2016/0319 entitled 'Exploring the experiences of young people living with malignant melanoma within a relational context: an interpretive phenomenological analysis'

The Research Governance Framework for Health and Community Care outlines the responsibilities of both employers and employees who undertake research in a clinical setting. The framework has been compiled by the Scottish Executive Health Department to ensure all research meets high scientific and ethical standards.

This Letter of Clinical Research Access defines the requirements of Lothian Health Board (the "Board"), subject to which, you are granted rights of Clinical Research Access to carry out Approved Research in the course of your employment with **Edinburgh Napier University**. Under the terms of this letter you are specifically excluded from undertaking work involving access to patients which has a direct bearing on their care, unless you hold an Honorary Contract with the Board.

As an employee of **Edinburgh Napier University**, on signature of this letter, you will be granted the right of Clinical Research Access which will continue, until such time as permission is withdrawn by the Board, in the circumstances mentioned in the next paragraph, or such time as you cease to be involved in Approved Research activity or cease to be employed in your present capacity.

In the event that you are in material breach of the requirements regarding Clinical Research Access as set out in this letter, or the Board considers that it is in the best interests of its patients, then in either circumstance the Board may withdraw Clinical Research Access with immediate effect by giving you written notice of this.

1. Definitions

"Approved Research"

means research which has not only been approved by your employer (**Edinburgh Napier University**), but has also received the approval of Lothian Health Board i.e. R & D Management approval, the necessary ethical approval and any further statutory approvals. "Clinical Research Access" means access to identifiable patient data, organs, tissue or other material.

"Confidential Information"

includes all information which has been specifically designated as confidential by the Board and any information which relates to the commercial and financial activities of the Board, the unauthorised disclosure of which would embarrass, harm or prejudice the Board.

Letter of Clinical Research Access – Final December 2016

"Principal Investigator"

means, in relation to a specific unit of research undertaken in a specific location, the researcher responsible for the overall conduct of that research activity.

2. Confidentiality and Disclosure of Information

You must not divulge Confidential Information to any third party during the period of your research or any time thereafter without the proper authority having first been given.

All Confidential Information belonging to the Board, together with any copies or extracts thereof, made or acquired by you in the course of research shall be the property of the Board and must be returned to the Principal Investigator on completion of the research to which they relate or on the termination of your employment whichever is the earlier date. You will be entitled to retain any copies or extracts made or acquired by you in the course of research for references purposes only, provided that such copies or extracts are held and maintained in accordance with the provisions of the Data Protection Act 1988 and Caldicott principles.

3. Protection of Intellectual Property

The protection of intellectual property is an important matter, and you will abide by the requirements of the Board and **Edinburgh Napier University** in relation to this matter. The Board and **Edinburgh Napier University** deal with intellectual property matters on a case-by-case basis.

4. Obligations Arising from Data Protection Act 1998/IT Security

Particular regard should be given to your responsibility to abide by the principles of the Data Protection Act 1998, a copy of which is available for reference in the Human Resources Department of the Board.

You must comply with the Board's Information Technology Security Policy on computer security, which is available within the Board R & D Department and on the Board Intranet site. Failure to comply with this will be brought to the attention of your employer for investigation/action under the appropriate procedures. In addition failure to comply may lead to temporary or permanent withdrawal of permission to carry out research within the Board.

Patients

In the course of your duties you may have access to Confidential Information regarding patients. You must not divulge such Confidential Information to anyone other than authorised persons, for example, medical, nursing or other professional staff as appropriate, who are concerned directly with the care, diagnosis and/or treatment of the patient. Where, in the course of your clinical research activity, new information comes to light that will or may impact on patient care, you will forthwith advise the relevant personnel within the Board.

Staff

You must not divulge Confidential Information concerning individual members of staff to anyone without the authority of the individual concerned and the appropriate Principal Investigator.

If you are in any doubt whatsoever as to the authority of a person or body asking for information on patients or staff, or your own authority to divulge information, you must seek advice from your Principal Investigator.

These provisions are without prejudice to the NHS's stated commitments in the NHS Code of Openness. Further information is available from the Board's Human Resources Department.

5. Disclosure of Concerns

If you have any concerns about quality of service, health and safety, use of NHS money, or believe a colleague's conduct, performance or health may be a threat to patient care or to members of staff, you have a responsibility to raise these concerns without prejudice, directly with your line manager or Principal Investigator. If you are unable to, or wish not to raise these concerns directly with your line manager / Principal Investigator, you are encouraged to seek the advice of the Human Resources Department or **Edinburgh Napier University** as appropriate.

You are protected against any harassment or victimisation resulting from such a disclosure. Therefore in the event that you are subjected to any form of harassment or victimisation, formal action will be taken against the perpetrators.

Concerns related to any research misconduct or fraud should be addressed similarly.

6. Conflict of Interest

As a general principle, you should not put yourself in a position where your official and private interests conflict, nor must you make use of your official/research position to further your private interests.

7. Research Governance

You are required to observe those requirements of the Research Governance Framework which are applicable and binding on you. The Research Governance Framework is available in the R & D Department and on the Intranet under Organisational/R&D. The framework relates to the management and monitoring, ethics, science, finance, health and safety aspects of research.

8. Health and Safety

The Board has a written Health and Safety Policy. The Board has a duty to ensure, so far as is reasonably practicable, the health, safety and welfare at work of all its employees/individuals who work on the site. As an individual who works on the site, you have a duty to observe safe systems of work at all times, to take reasonable care of yourself and others who may be affected by your activities at work and to co-operate with the Board and others in meeting statutory requirements. Additionally, you are required to report all accidents "near misses"/ incidents to your Principal Investigator and to use any safety equipment provided for your protection.

Failure to comply with the provisions detailed above, without reasonable cause, will be brought to the attention of your employer for investigation/action under the appropriate procedures. In addition failure to comply may lead to temporary or permanent withdrawal of permission to carry out research within the Board.

9. Hepatitis B

For your own protection, you are advised to maintain Hepatitis B immunity status throughout the period during which you have been granted Clinical Research Access rights if your work brings you into contact with blood, other body fluids or fresh tissue.

10. Professional Registration

If your substantive post requires professional registration you must be fully registered with the appropriate professional body and maintain this registration throughout the period during which you have been granted Clinical Research Access rights. Evidence of this must be produced upon request.

Letter of Clinical Research Access – Final December 2016

11. **Personal Property**

The Board accepts no responsibility for damage to, or loss of, personal property. You are, therefore, advised to take out an insurance policy to cover your personal property.

If you need any further advice or guidance on any of the paragraphs set out above you should contact your Principal Investigator in the first instance.

If you agree to accept the conditions indicated above, please print this letter and sign the statement of acceptance and return to the Board's R & D Department. Please retain a second signed copy of this letter for future reference as you will be required to provide this for evidence of clinical research access to each Principal Investigator with whom you work.

Yours sincerely

Heather Charles

Dr Heather Charles
Head of Research Governance

cc. Shona Fitzpatrick, Edinburgh Napier University

(DO NOT DETACH)

Form of Acceptance

I hereby accept the conditions set out in the foregoing letter.

Print Name: (Block Capitals)

Employer/Organisation:

Signature: _____

Date: _____

Appendix 3: Research Access – NHS Grampian.

Research & Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Mrs Wendy McInally



Date 16th December 2016
Enquiries to Dr Khyati Parikh
Extension 51119
Direct Line 01224 551119
Email k.parikh@nhs.net

Dear Mrs McInally

Letter of access for research

This letter confirms your right of access to conduct research through NHS Grampian for the purpose and on the terms and conditions set out below. This right of access commences on 16th December 2016 and ends on 12th December 2017 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at NHS Grampian has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to NHS Grampian premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Grampian, you will remain accountable to your employer, Edinburgh Napier University but you are required to follow the reasonable instructions of Professor Maggie Cruickshank of this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

*NHSG letter of access for university researchers who do not require an honorary research contract
Version 1*

Page 1 of 2

You must act in accordance with NHS Grampian policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Grampian in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Grampian premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

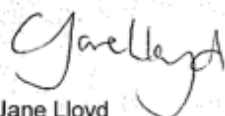
You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

NHS Grampian will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation as well as the Research and Development Office.

Yours sincerely



Jane Lloyd
Human Resources Team Leader, NHS Grampian

cc: R&D office at NHS Grampian
HR department of the substantive employer

Appendix 4: Research Access – NHS Greater Glasgow & Clyde



Administrator: Mrs Elaine O'Neill
Telephone Number: 0141 232 1815
E-Mail: elaine.o'Neill2@ggc.scot.nhs.uk
Website: www.nhs.gov.uk/r&d

Research & Development
West Glasgow ACH
Dalnair Street
Glasgow G3 8SW

09 February 2017

Mrs Wendy M McNally



Dear Mrs W McNally,

Letter of Access for Research

This letter confirms your right of access to conduct research through **NHS Greater Glasgow and Clyde** for the purpose and on the terms and conditions set out below. This right of access commences on **09/02/2017** and ends on **09/04/2018** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at **NHS Greater Glasgow and Clyde** has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to **NHS Greater Glasgow and Clyde** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **NHS Greater Glasgow and Clyde**, you will remain accountable to your employer **Edinburgh Napier University** but you are required to follow the reasonable instructions of **Dr David Dodds** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **NHS Greater Glasgow and Clyde** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **NHS Greater Glasgow and Clyde** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care

for the health and safety of yourself and others while on **NHS Greater Glasgow and Clyde** premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the health board's HR department prior to commencing your research role at the Health board.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

NHS Greater Glasgow and Clyde will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Mrs Elaine O'Neill

Senior Research Administrator

cc: Shona Fitzpatrick (Napier University)

Appendix 5: Edinburgh Napier University Ethics Approval

Edinburgh Napier
UNIVERSITY



Edinburgh Napier University
School of Nursing, Midwifery and Social Care
Research Integrity Committee
9 Sighthill Court
Edinburgh
EH11 4BN

3 May 2017

Dear Wendy

Project Title: People living with malignant melanoma within a relational Exploring the experiences of young people with malignant melanoma; an interpretive phenomenological analysis.

Project start date: February 2015

Project reference: FHLSS/1787 Version no. 2

Further to your application for Ethical approval to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee have approved your application and we wish you all the best with your study.

May I remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project and provide notification of study completion. All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,

Dr. Barbara Neades
Chair



INVESTOR IN PEOPLE

Edinburgh Napier University is a registered Scottish charity Reg. No. SC018373

Inspiring Futures
www.napier.ac.uk

Appendix 6: Patient Information Sheet – Young Person

Participant Information Sheet: Young Person

Version 4 21/10/16



Participant Information Sheet – Young Person

Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
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Participant Code:	
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What is the purpose of the study?

This research study aims to explore young people's experiences of living with malignant melanoma and will include a family member who is fundamental to the overall cancer journey. You will be asked by the Clinical Nurse Specialist who will provide you with this a Participant Information Letter to identify one key family member. This is your choice. The family member needs to be identified at this time or when giving consent. Please take the time to read the information in this sheet about this study and feel free to ask if you have any questions.

Why have I been asked to take part?

You have been chosen to take part in this study as you have been diagnosed with malignant melanoma. Your experiences are important in helping us to understand your needs. The study will aim to recruit from three NHS hospital treatment centres in Scotland.

Do I have to take part?

No, you do not have to take part in this study. It is entirely up to you whether or not to take part. If you do so, you will be given this information letter to keep. Also if you decide to participate you are free to withdraw at any time and without giving a reason. If you decide to withdraw, any data you have provided will be safely destroyed and will not be used in any publication.

What will happen if I take part?

You will be contacted by the Clinical Nurse Specialist who will provide you with this Participant Information Letter. This will be given to you a week before so you have time to think about being part of the study. If you agree to take part, the CNS will let the researcher know and they will be responsible for ensuring you sign a consent form before being interviewed. There will be no right or wrong answers. Your responses will be confidential and anonymous. You will then take part in one interview. The interview will be at any part of the cancer journey. The interview will last no longer than 1 hour. The interview will take place at a time and place that is convenient to you within the hospital environment. You may wish to be interviewed with your family member present or on your own, it is entirely your choice. At the interview you will be asked how malignant melanoma has affected your life; what, if anything, has changed, and what has stayed the same. There will be some prompts/guidance given to help you think about this. For example, you will be asked about what sources of support you have used and what has been helpful or unhelpful. This is an example of what may be asked. If you agree, the interview will be tape recorded and then typed. If you wish you can read through the typed interview to make sure it is accurate.

What are the possible benefits of taking part?

The results of this study will be used to inform and develop services locally, nationally and internationally for young people with malignant melanoma and their family. This study is to improve the services for young people with this type cancer in the future.

Participant Information Sheet: Young Person V4 – October 2016

Participant Information Sheet: Young Person

Version 4 21/10/16

Edinburgh Napier
UNIVERSITY



What are the possible disadvantages and risks of taking part?

I know that this may be a stressful time for you. It is possible that by discussing your experiences you may become upset. If this happens I will offer to stop the interview immediately. I will offer to provide additional support to you at this time either by talking things through with you or by contacting someone you feel comfortable with. This may be your CNS or Doctor.

Will my decision to take part or to decline have any effect on the care I receive?

Your decision to take part or to decline will not affect the standard of care you receive in any way. If you agree to take part now, you can withdraw from the study at any time without explanation.

Will my taking part in the study be kept confidential?

If you are willing to take part in the study, all information about you and the responses that you give will be confidential. No personal information will be used. Your responses will be collated with other participant's responses. All data will be stored on a password protected computer with no personal identifiable information. Your name will be replaced with a participant code and it will not be possible for you to be identified in any reporting of the data gathered. You can see your unique participant code at the top of all the documents within this project pack. If you wish to leave the project at any time, you do not need to identify yourself to the Research Team; you just need to give them your participant code. All data collected will be kept in a secure place (paper copies of questionnaires will be kept locked cabinet in locked room/electronic data will be stored in a password protected computer). Access to data will be strictly limited to the research team. All transcripts will be destroyed following 5 years of completion of the project. The study has been given a favourable ethical opinion by the Research Ethics Committee of the Edinburgh Napier University. The results may be published in a scientific journal or presented in a report and at scientific conferences. You will not be identified in these publications by any of the information provided. The sponsor of the study, Edinburgh Napier University, may ask to see anonymised data. You will not be identified by any information provided in these data.

What will happen to the results of the study?

A full report of this study will be submitted to Edinburgh Napier University for assessment for the award of Doctor of Philosophy. Some results will be submitted for publication in professional journals and presented at conferences. Participants will not be identifiable in any of these reports.

Who has reviewed this study?

This study has been reviewed by Edinburgh Napier University Research Ethics committee for ethical approval.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from South East Scotland REC 2. NHS management approval has also been obtained.

What happens when the study is finished?

A full report of this study will be submitted to Edinburgh Napier University for assessment for the award of Doctor of Philosophy.

Participant Information Sheet: Young Person

Version 4 21/10/16



What if there is a problem?

If you have any questions and / or concerns about any aspect of this project, you should ask to speak with the, Wendy McNally, who will do her best to answer your questions. If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Janyne Afseth, Lecturer Edinburgh Napier University (j.afseth@napier.ac.uk).

Who is organising the research and why?

If you are interested in being interviewed, you will be contacted by the researcher who will arrange a meeting at a convenient location and time. After the interview you will be provided by a Participant Debrief. The debrief letter is for you to keep and contains further information regarding sources for support. You can also keep this information letter, if you wish. Your participation in this study is a one-off and you will not be contacted again in relation to this study. Many thanks for your consideration.

Wendy McNally SFHEA MSc BSc (Hons) RSCN.
Chief Investigator.
Edinburgh Napier University
9 Sighthill Court
Edinburgh EH11 4BN
Email: w.mcinally@napier.ac.uk.
Telephone: 0131-455-5343.

Appendix 7: Patient Information Sheet – Family/Significant Other

Participant Information Sheet: Family

Version 3 17/10/16

Edinburgh Napier
UNIVERSITY



Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
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Participant Code:	
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What is the purpose of the study?

You are being invited to take part in a research study. You are a family member of a young person who has malignant melanoma. Before you take part, it is important for you to understand why the research is being done and what it will involve. Ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Why have I been asked to take part?

You are a family member of a young person who has been diagnosed with malignant melanoma. This may be your child, a sibling, or partner for example at diagnosis, mid treatment or at the end of their treatment. The study will aim to recruit from three NHS hospital treatment centres in Scotland.

What will happen if I take part?

This research study aims to explore the young person's experiences of living with malignant melanoma and will include the family who are fundamental to their overall cancer journey. Please take the time to read the information in this sheet about this study and feel free to ask if you have any questions.

What does the project entail?

You will be contacted by the Clinical Nurse Specialist who will provide you with this Participant Information Letter. If you agree to take part, you will have to sign a consent form before being interviewed. There will be no right or wrong answers. Your responses will be confidential and anonymous. The interview will last no longer than 1 hour. The interviews will take place at a time and place that is convenient to you within the hospital environment. If you agree, the interview will be tape recorded and then typed. If you wish you can read through the typed interview to make sure it is accurate.

Do I have to take part?

No, you do not have to take part in this study. It is entirely up to you whether or not to take part. If you do so, you will be given this information letter to keep. Also if you decide to participate you are free to withdraw at any time and without giving a reason. If you decide to withdraw, any data you have provided will be safely destroyed and will not be used in any publication.

Will my taking part in the study be kept confidential?

If you are willing to take part in the study, all information about you and the responses that you give will be confidential. No personal information will be used. Your responses will be collated with other participant's responses. All data will be stored on a password protected computer with no personal identifiable information. Your name will be replaced with a participant code and it will not be possible for you to be identified in any reporting of the data gathered. You can see your unique participant code at the top of all the documents within this project pack. If you wish to leave the project at any time, you do not need to identify yourself to the Research Team; you just need to give them your participant code. All data collected will be kept in a secure place (paper copies of questionnaires will be kept locked cabinet in locked room/electronic data will be stored in a password protected computer). Access to data will be strictly limited to the research team. All transcripts will be destroyed

Participant Information Sheet: Family V3 October 2016

Participant Information Sheet: Family

Version 3 17/10/16



following 5 years of completion of the project. The study has been given a favourable ethical opinion by the Research Ethics Committee of the Edinburgh Napier University. The results may be published in a scientific journal or presented in a report and at scientific conferences. You will not be identified in these publications by any of the information provided. The sponsor of the study, Edinburgh Napier University, may ask to see anonymised data. You will not be identified by any information provided in these data.

What are your rights?

Participation in the project is entirely voluntary and you are free to refuse to take part or to withdraw from the project at any point without having to provide a reason and without any consequences. If you wish to withdraw, you can contact the research team, give them the participant code printed on this letter and on your debriefing letter and the researchers will withdraw your data. You do not need to provide your name. Your decision about whether to participate in the project will have no influence on your current employment. Your responses to the interview questions will be confidential. You need to be aware that if you disclose information regarding criminal activity or serious breach of professional code of conduct, the researchers will have to break confidentiality and take appropriate action.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part in this study. However, many people find it interesting and helpful to take part in similar studies and reflect on how they feel. Your participation may benefit young people with malignant melanoma and their families/carers by increasing our understanding of the cancer journey and best practice.

What are the possible disadvantages and risks of taking part?

I know that this may be a stressful time for you. It is possible that by discussing your experiences you may become upset. If this happens I will offer to stop the interview immediately. I will offer to provide additional support to you at this time either by talking things through with you or by contacting someone you feel comfortable with. This may be the CNS or Doctor. You can take breaks if you are tired or concerned and even re-schedule the meeting for another date, if you wish. You will be given time to ask any questions before you give your consent and at any point during or even after your participation in the study.

What if there is a problem?

If you have any questions and / or concerns about any aspect of this project, you should ask to speak with, Wendy McNally, who will do her best to answer your questions. If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Janyne Afseth, Lecturer Edinburgh Napier University (j.afseth@napier.ac.uk).

Participant Information Sheet: Family

Version 3 17/10/16



What happens when the study is finished?

A full report of this study will be submitted to Edinburgh Napier University for assessment for the award of Doctor of Philosophy.

What will happen to the results of the study?

Some results will be submitted for publication in professional journals and presented at conferences. Participants will not be identifiable in any of these reports.

Who has reviewed the study?

This study has been reviewed by Edinburgh Napier University Research Ethics committee for ethical approval. Approval for a research passport is also required for each of the three NHS boards.

Who is organising the research and why?

If you are interested in being interviewed, you will be contacted by the researcher who will arrange a meeting at a convenient location and time. After the interview you will be provided by a Participant Debrief. The debrief letter is for you to keep and contains further information regarding sources for support. You can also keep this information letter, if you wish. Your participation in this study is a one-off and you will not be contacted again in relation to this study. Many thanks for your consideration.

Wendy McNally SFHEA MSc BSc (Hons) RSCN.
Chief Investigator.
Edinburgh Napier University
9 Sighthill Court
Edinburgh EH11 4BN
Email: w.mcinally@napier.ac.uk
Telephone: 0131-455-5343.

Appendix 8: Consent Form – Young Person

Consent Form: Young Person

Version 5 27/10/16



Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
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Participant ID:	
------------------------	--

Chief Investigator:	Wendy McNally
Contact Details:	Email: w.mcinnally@napier.ac.uk Telephone: 0131-455-5343.

Questions (Please initial the appropriate box):	YES	NO
1. I have read and understood the Participant Information Letter.		
2. I have been given an opportunity to ask questions and further discuss this project.		
3. I agree to participate in the study by being interviewed.		
4. I understand that any information provided will be kept confidential.		
5. I understand the limitations of confidentiality, i.e. that the researcher will have to take appropriate action if in danger of harm to yourself and others.		
6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Edinburgh Napier University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.		
7. I understand that I am under no obligation to take part in this study.		
8. I understand that participation is entirely voluntary and that I am free to withdraw from the study at any time without giving a reason.		
9. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the sponsor Edinburgh Napier University. I give permission for these individuals to have access to my records.		
10. I agree to my General Practitioner being informed of my participation in this study.		
11. I agree to take part in the above study.		
12. I understand that my personal information will be anonymised for publication.		

If your answer is YES to all the above, please sign the consent form and hand it back to the researcher BEFORE your interview.

	Participant	Researcher
Name:		
Signature:		
Date:		

Consent Form: Young Person V5 October 2016

Appendix 9: Consent Form – Family/Significant Other

Consent Form: Family

Version 4 21/10/16

Edinburgh Napier
UNIVERSITY



Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
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Participant ID:	
------------------------	--

Chief Investigator:	Wendy McNally
Contact Details:	Email: w.mcinnally@napier.ac.uk Telephone: 0131-455-5343.

Questions (Please initial the appropriate box):	YES	NO
1. I have read and understood the Participant Information Letter.		
2. I have been given an opportunity to ask questions and further discuss this project.		
3. I agree to participate in the study by being interviewed.		
4. I understand that any information provided will be kept confidential.		
5. I understand the limitations of confidentiality, i.e. that the researcher will have to take appropriate action if in danger of harm to yourself and others.		
6. I understand that I am under no obligation to take part in this study.		
7. I understand that participation is entirely voluntary and that I am free to withdraw from the study at any time without giving a reason.		
8. I understand that anonymised data will be analysed and the anonymised results and/or anonymised quotes maybe be used in scientific reports and publications.		
9. I understand that the sponsor of the study, i.e. Edinburgh Napier University, might have access to anonymised data.		
10. I agree to take part in the above study.		

If your answer is YES to all the above, please sign the consent form and hand it back to the researcher BEFORE your interview.

	Participant	Researcher
Name:		
Signature:		
Date:		

Consent Form: Family V4 October 2016

Appendix 10: Risk Assessment Proforma

Risk Assessment Proforma

Student Name: Wendy McNally

Edinburgh Napier
UNIVERSITY



Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
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Date(s) to be carried out:

August – March 2017 although this will be dependent on patients at this particular time and ethical permission.

List here any potential risks you (as researcher) may face in carrying out this research;

Potential risks to the researcher;

Possible bias as the researcher was a specialist children's oncology nurse and have read widely as an academic around young people living with and beyond a cancer diagnosis. Being subjective as opposed to listening carefully to what they are communicating. Due to the sensitive nature of the study there is a risk of becoming emotionally involved. Dealing with experiences that affect the overall patients care.

Outline the measures/steps you are putting in place to minimise these risks:

Training, preparation, and supervision will be taken into account so that the risk to the researcher can be minimized. Due to the nature and sensitivity of this research this will be sought throughout the whole process.

Students carrying out research off-campus should complete the following:

Where I am going?*

Aberdeen, Glasgow and Edinburgh NHS Hospital/clinic environment.

How I am getting there (including travel route)?

By bus/car/train

What to do should I not return at the specified time?

I will be in contact at all times through mobile phone.

This person will be my Line Manager:

Karen Campbell.

Ensuring to maintain participant confidentiality

I am bound by this through my registration as a nurse.

Outline here the procedure you will be using to do this:

At all time and as a registered nurse the researcher will adhere to participant confidentiality (NMC 2015). All information gathered will be kept confidential unless participants discuss their dissatisfaction with the health care system the researcher will seek participants permission to disclose the information from the interview to the relevant authority. This is in keeping with Nursing and Midwifery Council (NMC) (2015) guidance on the code of professional practice for nurses and midwives.

All participant involvement will be anonymous. Only the researcher and supervisors will have access to the audio files and transcripts which will be password protected through the computer. These materials will be destroyed after completion of the study and participants will be informed of this. Destroying of all the materials is in accordance with the Data Protection Act (1998).

Risk Assessment Proforma Version 2 5th September 2016

Risk Assessment Proforma

Student Name: Wendy McNally



	Supervisor	Student
Name:		
Signature:		
Date:		

Appendix 11: Research Debrief – Young Person and Family/Significant Other

Proposed Interview Schedule: Family



Title:	Exploring the Experiences of Young People Living with Melanoma within a Relational Context.
---------------	--

Research Summary:

Thank you for agreeing to participate in the interview.

As this study seeks to find out the process young people go through following a diagnosis of melanoma and what their experiences are of the support and care during this time, your views and experiences are important. There are no right or wrong answers; it is your perceptions and experiences that are important here.

To begin with I'd like to ask you a bit about your role around the time the young person with melanoma was diagnosed and thereafter treated for melanoma depending on the stage of diagnosis. The young person has chosen the family member who is most important in their care and journey.

- What is your experience of caring for your family member with melanoma? How has it been for you?
- Has your life changed/been affected in any way and how? (In a positive/negative way)?
- What are the challenges you have been faced with during this time as a family member?
- What has gone well and what has not gone so well during this experience? (Probes: care, treatment, support) Could you give me an example?
- How has your relationship with the young person changed or not during this experience? (Probes: impact, family, social)
- Is there anything else you would like to talk about in relation to your experience of living with young person with melanoma that we haven't covered?
- How was your experience of being interviewed for this project?

Chief Investigator:

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9 Sighthill Court
Edinburgh EH11 4BN
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Telephone: 0131-455-5343.

Appendix 12: Interview Schedule – Young Person

Proposed Interview Schedule: Young Person



Title:	Exploring the Experiences of Young People Living with Malignant Melanoma within a Relational Context.
---------------	--

Research Summary:

You have been asked to take part in this study as you have been diagnosed with malignant melanoma. For this study I would like to find out how this particular cancer has affected young people and how they are learning to live with it. I will also be asking for you to choose a significant family member that is experiencing this journey with you. There are no right or wrong answers; it is your experiences that are important here. Probes will be used to facilitate discussion of personal experiences, aids memory recall and taps into and uncovers a range of both negative and positive thoughts. I will have semi-structured questions to encourage the flow of discussion.

- To begin with I'd like to learn a bit about your journey to being diagnosed with malignant melanoma.
- What things stick in your mind about the time leading up to diagnosis?
- What stands out for you from your experience through this journey from diagnosis, to treatment or after treatment? (Probes: diagnosis, treatment, after treatment)
- How has this cancer affected your life? (Probes: Self, daily life, work, social, relationships....)
- How has your life changed as a result of your cancer? (Probes: negative and positive changes?)
- What are your main concerns at this time?
- How do you feel about the support you have at the moment? What support do you need just now? (Probes: family, nurse specialist etc?)
- Is there anything else you would like to talk about in relation to your experience of living with malignant melanoma that we haven't covered?

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Telephone: 0131-455-5343.

Appendix 13: Interview Schedule – Family/Significant Other

Proposed Interview Schedule: Family



Title:	Exploring the Experiences of Young People Living with Melanoma within a Relational Context.
---------------	--

Research Summary:

Thank you for agreeing to participate in the interview.

As this study seeks to find out the process young people go through following a diagnosis of melanoma and what their experiences are of the support and care during this time, your views and experiences are important. There are no right or wrong answers; it is your perceptions and experiences that are important here.

To begin with I'd like to ask you a bit about your role around the time the young person with melanoma was diagnosed and thereafter treated for melanoma depending on the stage of diagnosis. The young person has chosen the family member who is most important in their care and journey.

- What is your experience of caring for your family member with melanoma? How has it been for you?
- Has your life changed/been affected in any way and how? (In a positive/negative way)?
- What are the challenges you have been faced with during this time as a family member?
- What has gone well and what has not gone so well during this experience? (Probes: care, treatment, support) Could you give me an example?
- How has your relationship with the young person changed or not during this experience? (Probes: impact, family, social)
- Is there anything else you would like to talk about in relation to your experience of living with young person with melanoma that we haven't covered?
- How was your experience of being interviewed for this project?

Chief Investigator:

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Proposed Interview Schedule: Family Version 2 5th September 2016

Appendix 14: Using The Microsoft Software Suite

Content	Participant	Comment	Making Initial Noting
First of all, just to let you understand this is study as part of my PhD, and we are going to be using IPA which is interpretive phenomenological analysis. It is really about your experience of your journey so far, right from when you were diagnosed with melanoma. So, what might be a good place to start is that you tell me a bit about yourself?	Interviewer		Icebreaker
I was born in Edinburgh, lived here my whole life and went to school down in Leith and went to the high school at Leith academy. I was diagnosed when I was 16, so that was the start of my sixth year at school, so I took out a bit of time off from school then, I think I was diagnosed on the 21st of October and I think I got the all clear towards the start of December, so it was a pretty short period of time. But it didn't feel short, it felt quiet long. After that, post cancer, I took a bit more time off school, the school were great, the school were really good at easing me back into it and not forcing me into anything that I wasn't will to do at the time. After that I had my interview at university to go to study journalism and he had said that I needed to get one more B because I was currently sitting on 3 Highers and they were looking for four. I explained my situation and he said it would be great if I could get one higher which happily I did and I got my B in Biology which meant I could go to university straight out of school.	1a	<p>Short time – felt long for the YP.</p> <p>Uncertainty about his exams</p> <p>Pressure of exams and staying on top of his school work</p>	<p>Life on hold</p> <p>Trying to normalise his life</p> <p>Worried about exams</p> <p>Worried about his future</p>
Thank you. I am just going to take you back a bit to the experience at that time when you were 16, looking forward to your life after school, going onto university and things. What were thoughts at this time about having this disease and moving on with your life?	Interviewer		Trying to probe, to recall his journey at this time and how he made sense of his world.
Yeah, 100%. When I look back at it now it seems like a different part of my life, it seems like it was sort of taken out of it and I look at it as a different space. Because I have now had time now to reflect on it and reflection has been a big thing for me looking back, I've been able to look back at it as a different chunk and be able to comprehend what had happened and to think about it quite clearly. But at the time it did feel like this wasn't in the schedule. Because when you're in Sixth year you do get a map off your teachers, and they say you do this, you'll revise for your exams and then you'll start getting in contact with the college or university. So, it did feel like where did this, who wrote this into my plan.	1a	<p>Not happening to me?</p> <p>Different journey than one on.</p>	Looking forward to life then bang cancer.

Appendix 15: Six-Step Development of Emerging Themes – Steps 1 & 2

Step 1 and 2 – Reading, Re-reading and Initial Noting

Transcript	Participant	Comments	Themes Emerging
<p>No, I think my mum who is a nurse; she was a bit more sceptical about it. But, throughout, when the mole came up on my neck, I, stupidly, just thought it was a spot, I thought I was at that age and I just thought, oh no, I am starting to get spots, so I was putting things like Sudocream on it. And then...</p>	1a - John	<p>Not sure what it was</p> <p>Relying on mother's knowledge</p> <p>Not really bothered by it</p> <p>Just his age, so apply cream to the 'spot'</p>	<p>Being bewildered</p> <p>Ambiguity of not really knowing or understanding what he had found</p> <p>Is it serious, not really sure?</p>
Was it sore, did you have any discomfort from the mole?	Interviewer		
<p>no, it wasn't it was a tiny bit raised and the circumference of it started to increase slowly and we been back and forwards to the doctor and they had assured us it was OK and that was down at my local GP.</p>	1a	<p>Mole changing</p> <p>Back and forward to G. P.</p>	<p>Delay in diagnosis</p>
<p>Yeah, I don't go very often but if something does crop up, I just go in there. I must have been twice, I went the first time and she said 'no, it not a problem' and then we went again because I was going on holiday to Tenerife and Mum was conscience that maybe this was something looking in to. And she said, 'I don't think this is anything to be worried about but go away on your holiday and if there are any problems when you come back, come back in and speak to me.' So then to take it back to what your question was and was I surprised? That was, I think that was the biggest shock, because I had been assured by other, who I saw as professionals and I thought ... and you trust your doctors. So, at my GP ... I think that was the thing from the start, prior to any diagnosis I was pretty chilled about it and then when I came up here to get the, they do a small excision to take out the mole and I was fine up till then, and then we got the phone call, which it was a bit early but I talk to my dad about it and we had come to the idea that it was just to check on my scar, because I had a tiny little scar at the time and I came in here and they said 'it's a melanoma'. And I didn't know what a melanoma was at the time, so, I stopped and when I said, 'what's a melanoma?' and they said, 'you got skin cancer' And then that... I think as soon as I heard the word cancer, because it had such a stigma to it, it did, it hit me like a ton of bricks at first. And I was in, it's in just like any other GP's room, it was in a very small room but that felt even smaller.</p>	1a	<p>Shock</p> <p>Cancer- hit me like a ton of bricks</p> <p>Had put his faith in his local doctor.</p> <p>Went on holiday as all ok</p> <p>Came back and all was surreal</p>	<p>No self-awareness</p> <p>Not serious</p> <p>Emotional impact and disbelief</p> <p>Recognises the word cancer not melanoma</p>

Appendix 16: Six-Step Development of Emerging Themes – Step 3

Step 3 – Developing Emergent Themes

Participant Transcript: George			Participant Transcript: Paul		
<p>Yes. Well I've got quite a lot of moles all over and never really paid attention to them because I knew they were there. So, I was off getting my haircut, and my hairdresser went 'that mole doesn't look right'. So, I made a doctor's appointment just to get checked, and they weren't happy with it, they weren't sure about it because it only just a little local doctor.</p> <p>Well we made the initial appointment for him and we saw a local man, who's from the same part of the country as myself, highlands understanding. He said 'aye' just send him up and we'll take it off.</p>			<p>I was absolutely shattered and in a lot of pain. I had to sit up in bed which was painful, I was out of breath constantly so it was a horrible night, horrible night, then of course, depression came back that night, so I was not suicidal but it would have been easier if I never woke up. I had strong painkillers but made me constipated. It was just the one night, mostly on my own, didn't want to wake my mum, I was a total shambles.</p>		
Interpretation Review:			Interpretation Review:		
Description / Content:	Language Use:	Interrogative coding:	Description / Content:	Language Use:	Interrogative coding:
Tell me about when you first noticed a change in your mole?	'never really paid much attention', 'off getting haircut'	No real signs or symptoms that there was something wrong with his mole, has may all over his body, never bothered him before, why now? Going about his daily routine Slightly worried but really not sure	What was it like for you when you went home, after discharging yourself early?	'absolutely shattered and in a lot of pain' 'out of breath constantly, horrible, horrible night'	Worry setting in, reality of the surgery and what had happened to him. Anxiety causing breathlessness in addition to the surgery. Community care from hospital discharge to home.
What prompted George to go to the Doctor?	'hairdresser, that mole doesn't look right'	No self-awareness or knowledge of moles Worried enough as hairdresser was worried Wanted to get it checked	Were you able to take medication to help with your pain?	'had strong painkillers but made me constipated'.	Treatment was followed through with medication Treatment and follow up care not satisfactory
Why did he trust the hairdresser? Richard, Georges father discussed how the mole was identified and taken seriously	Worried about the mole, uncertain of what it was Father made the initial appointment with a local GP whom he knew from where he came from	Trusting relationship with hairdresser Seeking reassurance Trusted the local doctor The doctor acted straight away, had an awareness that that something was not right from the father's phone call.	Did you have a community nurse to visit you?	'depression came back and it would have been easier if I never woke up'.	No psychological support Alone and afraid

Definition of terms used:	
Description/content:	What the interviewer was asking from the participant
Language Use:	Data from the original transcript
Interrogative coding:	asking questions of the data to facilitate a deeper coding and inquisitive attitude towards the data.

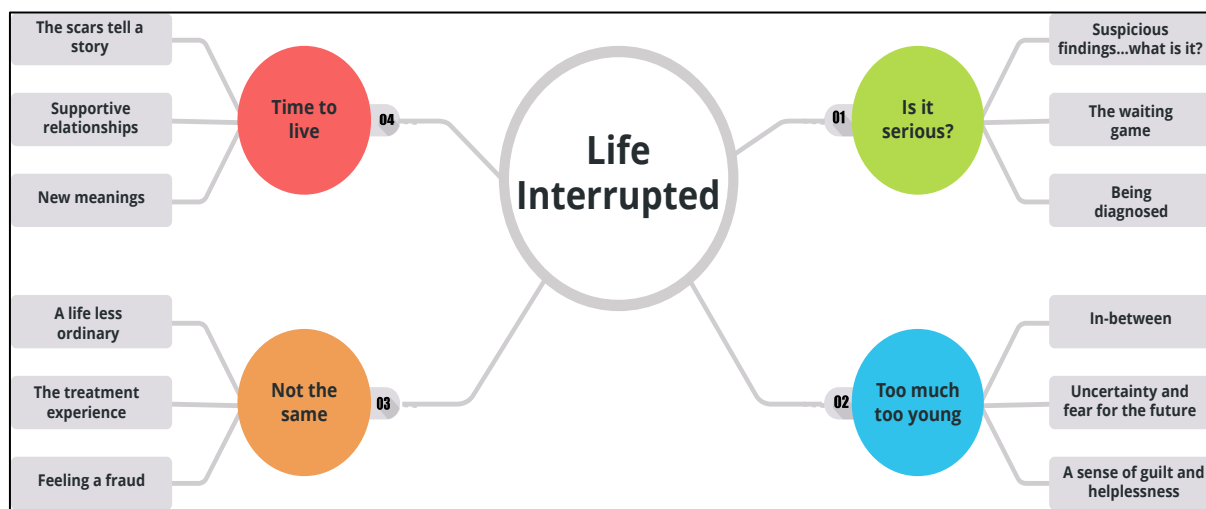
Appendix 17: Six-Step Development of Emerging Themes – Step 4

Step 4 – Searching for patterns across themes

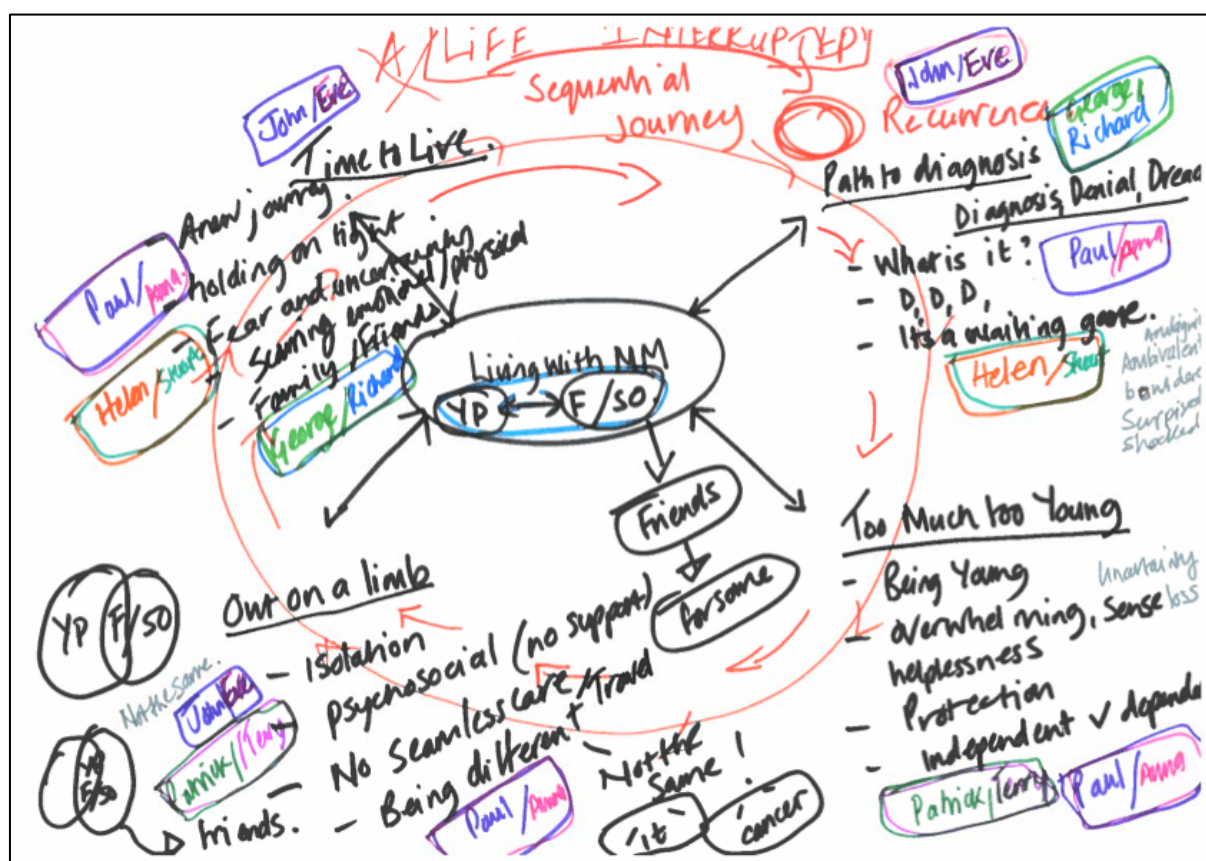
Colour Coding Key:	
Green	Normal mundane routine
Orange	Bewildered
Red	Unprepared/unexpected
Violet	Followed up with GP
Purple	Reassured
Yellow	Post-surgery unwell
Brown	Anxious, worried
Teal	No psychological support
Grey	Treatment experience
Dark Blue	Feeling alone, helpless
Light Blue	Loss of independence
Brown	Worry and fear

Appendix 18: A Thematic Map Mind-Map Representation of the Metanarrative, the Super-Ordinate and Sub-Themes

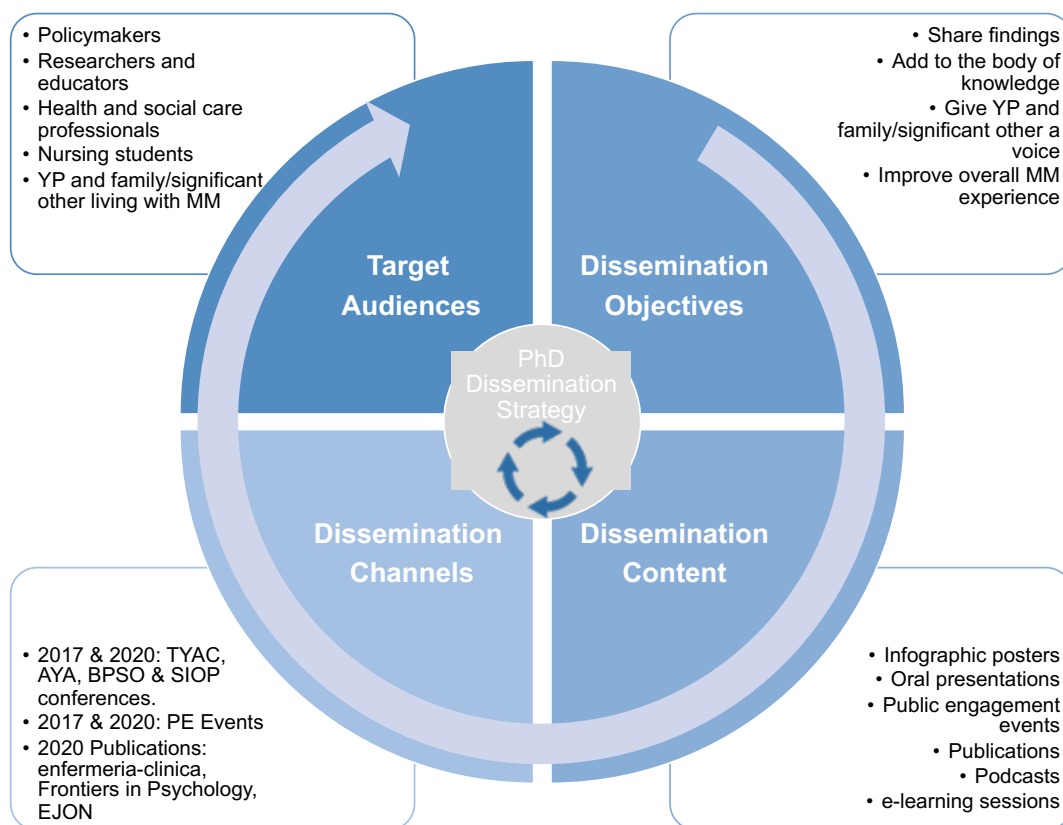
Mindmap:



Thematic Analysis:



Appendix 19: Dissemination Strategy



Appendix 20: Public Engagement Examples – BRIGHTLIGHT, TYAC Award and AYA



THERE IS A LIGHT: BRIGHTLIGHT

An original performance inspired by the findings of BRIGHTLIGHT, the first major study of its kind, There is a Light: BRIGHTLIGHT presents young patients' perspectives on specialist cancer care in England.

The event is being held from the **17th to 19th November 2017** in Edinburgh by The Youth Theatre Arts Scotland and the Cancer Collaborative Theme, Edinburgh Napier University. There will be a special matinee performance on the 18th for colleagues and students.

Contact w.mcinnally@napier.ac.uk for further information.

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Teenagers and
Young
Adults with
Cancer



**Lisa Thaxter Trust
Runner Up Prize 2017**



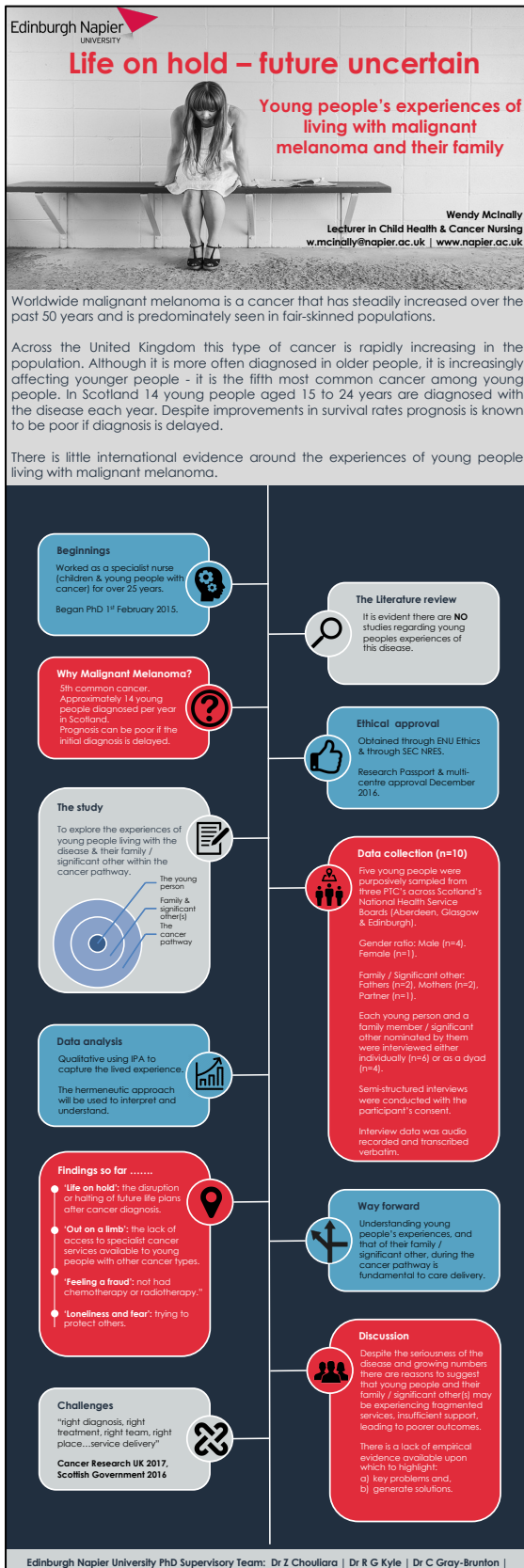
Awarded to

Wendy McNally

for the **Runner Up Best Poster presentation**
given at the TYAC/Brightlight Conference
6th—7th July 2017, at Horizon Leeds

On behalf of Teenagers and Young Adults with Cancer (TYAC)

Dr David Hobin, TYAC Chairman



Appendix 21: PGR Conference

A Life Interrupted – Future Uncertain

Young people's experiences of living with malignant melanoma: an interpretive phenomenological analysis

Wendy McInally
Lecturer in Child Health & Cancer Nursing

PhD Supervisory Team
Dr Zoe Choulis
Dr Rickard K
Dr Carol Gray-Brunt

Edinburgh Napier University

Malignant Melanoma

A Global Concern

Worldwide malignant melanoma is a cancer that has steadily increased over the past 50 years. It is predominately seen in fair skinned populations.

Malignant Melanoma

United Kingdom

The United Kingdom
In the United Kingdom it is the fifth most common cancer among young people.

In Scotland 14 young people are diagnosed with the disease each year, more common in male than female.

Despite improvements in survival rates prognosis is known to be poor if diagnosis is delayed.

Region	Number of cases
England & Wales	14
Scotland	14
Northern Ireland	14

Young People

Challenging Patient Group

Caring for young people with cancer

Different models of care.
Sufficient amount of literature around experiences of cancer in general.
No literature around experiences of young people with Malignant Melanoma.

Beginnings

Wendy McInally

Wendy McInally
Worked as a specialist nurse for over 25 years
Began PhD Feb 2015
Ethics granted in the Dec 2016/17, challenging as multi-centred

Research

Methodology

- 1 A qualitative exploratory study underpinned by Interpretive Phenomenological Analysis. Each participant at a different part of the cancer journey.
- 2 Five young people were purposively sampled from three National Health Service Boards (16 to 28 years) based on where they were receiving treatment. Four male and one female. Two mothers, two fathers and one partner. Stages 2 to 4.
- 3 Each young person and a significant other nominated by them were interviewed (n=10) either individually (n=4) or as a dyad (n=6). Semi-structured interviews with the participant's consent interview data was audio recorded and transcribed verbatim.

Research Methodology

Design

Developed in 1995 by Johnathan Smith
Double hermeneutics
Idiographic
Epistemological and ontological position
Concerned with narratives around lived experiences
Telling their story ... not mine, giving the narrative meaning.

Data Analysis

Hermeneutic Approach

Data Analysis

Key Steps

Key Steps Used

1. Reading & re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases
7. Writing up (not completed yet)

(Smith, Flowers & Larkin, 2009)

Research Methodology

Data Analysis

The main themes emerging

1. Life interrupted
2. Out on a limb
3. Feeling a fraud
4. Feeling alone and afraid

In their own words

11

Life Interrupted

"I was 16 years old following the mundane Monday to Friday school routine and trying to make my sixth and final year of school some sort of success"
P1

Out on a Limb

"I was in a ward where there were women with breast cancer – no access to the TKA unit"
P2

Feeling a Fraud

"I felt different from other people with cancer as I had my hair and didn't look like a cancer patient"
P3

Alone and Afraid

"There was no step by step guide on how to deal with it. And the suffering did not stem from my diagnosis but from those around me"
P4

Research Methodology

Findings So Far

12

Impact on the young people

Despite the seriousness of the disease there are reasons to suggest that young people and significant others may be experiencing a disruption to their world when a cancer diagnosis is given.

Young people with this disease experience fragmented services, insufficient support, leading to poorer outcomes.

Feeling not like other patients with cancer was evident as the treatment does not have the same side-effects.

Although the young people have a significant other they often feel alone as they struggled to be independent and live their life to the full.

Moving Forward

13

Timeline


1. Complete data analysis, feedback to CNSs (gatekeepers to study)
2. Continue to write Chapters
3. Present and publish
4. FINISH on time!

References


14

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Appendix 22: Publication

ISSN 2469-4193

**Comprehensive
Child and Adolescent
Nursing**
Building Evidence for Practice
Volume 41, Issue 1, 2018


Dr. Edward Alan Glasgow
Editor

Comprehensive Child and Adolescent Nursing

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Malignant Melanoma: How Do We Meet the Needs of Young People and Their Families?


Wendy McNally


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Malignant Melanoma: How Do We Meet the Needs of Young People and Their Families?

Wendy McNally

Department of Nursing, School of Health and Social Care, Edinburgh Napier University, Edinburgh, Scotland, United Kingdom

Malignant melanoma is a type of skin cancer that affects around 132,000 people across the globe every year (World Health Organization, 2017). If diagnosed early, prognosis is good. Yet, despite improvements in treatment that have driven improved survival, the incidence of malignant melanoma continues to increase in some countries, due to a combination of factors such as lack of awareness, light skin color, blonde or red hair, number of moles, family history, and excess exposure to ultraviolet (UV) radiation, particularly in childhood. Although malignant melanoma is more often diagnosed in older people, it increasingly affects adolescents and young adults (AYAs). In the United Kingdom (UK) for example, it is the fifth most common cancer in AYAs (Cancer Research UK, 2017; Information Services Department [ISD], 2017), and in Scotland, of the 180 young people between ages 15 to 24 years diagnosed with cancer every year, on average 14 will be diagnosed with malignant melanoma. In particular young females are more at risk than young males.

A study by Kyle et al. (2014) highlights the importance of awareness of skin cancer risk associated with UV exposure and encouraging sun protective practices. Such awareness and the establishment of protective health-related behaviors may have potential to reduce the burden of malignant melanoma in adolescence and early adulthood, as well as in later life. Malignant melanoma is an important disease within this age group and awareness of prevention and UV exposure is essential, as are early diagnosis and care management within age appropriate specialist services (Murray & Edgar, 2012).

Curative treatment is dependent on early diagnosis and the stage of the disease at diagnosis. The treatment for malignant melanoma varies depending on the stage of the disease. For all cases, treatment is usually surgical followed by immunotherapy which may be used as an additional treatment for high risk patients (Cancer Research UK, 2017). Clinical trials using immunotherapy are currently taking place, but optimal timing for this type of intervention has not been determined. Systemic treatment is used in

palliative and end of life care along with radiotherapy, especially for patients with metastatic disease. However, the recognition of early symptoms, in order that prompt diagnosis and treatment is available throughout the cancer pathway, is crucial (Zebrack, Kent, Keegan, Kato, & Smith, 2014).

Understanding and meeting the needs

In Scotland, the *Cancer Plan for Children and Young People* aims to ensure that children and young people aged between 0 to 25 years diagnosed with cancer have equal access to the best possible care and treatment as early as possible. The Managed Service Network (MSN) for Children and Young People with Cancer has been charged with delivering this vision (The Scottish Government, 2016). It is important that, as young people mature into adulthood, early diagnosis and defined care pathways are established. These pathways should consider the individual age, cancer type, and the future risks of late effects from treatment as well as the personal needs of the young person and their family.

Caring for young people with cancer requires a range of specific knowledge, skills, and experience to deliver often complex care regimes both within the hospital or in the community environment (Gibson & Soanes, 2008). A teenager or young person typically begins their cancer pathway within children's services, teenage cancer units, or adult services. In the UK they are given a choice of where they would prefer to be treated if they are between the ages of 19 to 24 years (National Institute for Health and Clinical Excellence [NICE], 2005).

A diagnosis of cancer can often occur at a time when the adolescent or young person is in the process of developing their early adult life plans and are at a major crossroads in their life (McInally, 2013). The diagnosis and subsequent treatment at this juncture may impact significantly on their life plans and their ability to fulfil their full potential. A diagnosis of cancer at this time may add to the stressors associated with a normal transition from young person to adulthood. It may also impact on their relationships, quality of life, and psychological wellbeing, among other components of their lives. The needs of the family cannot be separated from those of the individual with the disease, but both would value information and support offered in a structured way. Implications for practice suggest that young people wish to be empowered to take care of themselves.

Care delivery by competent health professionals who are knowledgeable about the immediate and long term implications of treatment is a fundamental requirement in order that young people and their families can be supported and prepared for what lies ahead. Services need to ensure clearly defined pathways are developed for the care of AYAs with malignant melanoma and review the effectiveness of these pathways on a regular basis.

However, there is a tendency to view the ideal treatment and care experience as arising out of specialist services that are age appropriate although this is not readily available for all AYAs with cancer across the globe due to different health care systems and resources (Carr, Whiteson, Edwards, & Morgan, 2013). This means that there is a need to ask what actually happens in practice from their own perspective and what information is given about services for ongoing care and support.

Next steps for research and practice

Existing literature reveals that there is no national or international research that focuses on the experiences of AYAs living with malignant melanoma. This can also be said for the experiences the families share with the adolescent endeavoring to cope with the disease. Previous research has tended to focus on the experiences of young people living with other types of cancer such as leukaemia and lymphoma rather than malignant melanoma (Murray & Edga, 2012). Thus, while models of young people's cancer experience have been developed (Taylor, Pearce, Gibson, Fern, & Whelan, 2013) it is not known whether these hold true for those diagnosed with malignant melanoma. Anecdotal evidence suggests that adolescents and young adults living with malignant melanoma may be experiencing fragmented services and insufficient support, potentially leading to poorer outcomes. Only by focusing on the experiences of young people living with malignant melanoma will services be designed that meet the needs of these young people and their families. The increasing incidence of the disease in Scotland and elsewhere makes this an even more important pursuit.

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Appendix 23: Public Engagement Event – 2 March 2020 – Ethics Approval, Itinerary, Evaluation and Images



Edinburgh Napier
UNIVERSITY



Edinburgh Napier University
School of Health and Social Care
Research Integrity Ethical Approvals
Committee
9 Sighthill Court
Edinburgh
EH11 4BN

26 February 2020

Dear Wendy

Project Title: Life Interrupted: Sharing the Journey
Project start date: 2/03/2020
Project end date: 01/06/2020
Project reference: SHSC20017

Further to your application for ethical approval to undertake a Public engagement/research study at Edinburgh Napier University as an external applicant, I am pleased to inform you that the committee has approved your application and we wish you all the best with your study. It is your responsibility to inform the SHSC ethics when your study has completed.

Data from your study should be held securely for a period agreed by the University's data mangment policy.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,



Dr. Anne Rowat
Chair



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Life Interrupted: Sharing the Journey Public Engagement Workshop Itinerary

Purpose:

The focus of the day will be to gather thoughts about the four key super-ordinate themes and 12 sub-themes that encapsulate the core conceptual thread of 'Life Interrupted'.

Workshop Itinerary and Timings

1045 – 1100:

Arrive at Sighthill Campus IPoint (reception on level 1). Wendy to meet you there.

1100: - 11:30

Welcome and introductions. An introductory pack will be provided with the PPT, and the findings. Completed consent forms for further research applications will be collected from participants.

1130 -1200:

Wendy will present a PowerPoint on the PhD, mainly focusing on data collection through to data analysis and findings. Workshop structured around the findings.

1200 – 1300: World Cafe

A 'world café' of four individual areas where the themes will be explored and the core conceptual thread, will be displayed on a board for participants to visualise and discuss whether this resonates with their journey and experiences of living with melanoma. The individual areas will be facilitated by the two supervisors and the core conceptual thread by Wendy.

The ten participants (young people, family and CNS) will be divided into two groups. This workshop will be facilitated by my two supervisors, Dr Richard Kyle and Dr Carol Gray-Brunton and Wendy.

There will be two key questions from this 'world café', 1) Do these findings resonate with your experiences of living with Melanoma at the time (three years have passed since the data was collected, 2) Is there any other experiences that have been not been included but worth mentioning?

Post it notes and pens will be used and flip chart and Wendy will collect all thoughts and sort into common themes. Anything 'new' will be added to the second part of the day after lunch. Wendy will place the flip charts on the walls for all to see whilst having lunch.

1300 – 1400:

Lunch.

1400 – 1445:

This part of the afternoon will focus on asking the participants about the findings and how they would like to see these disseminated? It will also focus on the young people and their family and where they are now.... three years on.

What now?

1445 – 1500: Sum up the day, Tip/Top summary. A evaluation card with be given with a Patient Information sheet and a

Participant Evaluation Questionnaire

Life Interrupted:

Tell us what you think.....

Question 1: Tell us how useful you found today's workshop? *(please circle)*



Question 2: Tell us why you thought this?

Question 3: Tell us what you think we should do with the findings?

Question 4: Tell us if you would be willing to be involved in future research? *(please circle)*



Images

